University of Alberta

From Devastation to Transformation: Managing Life When a Child is Disabled

by

Kathryn Ida Scorgie ©

A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfilment of the requirements for
the degree of Doctor of Philosophy

in

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **From Devastation to Transformation: Managing Life When a Child is Disabled** submitted by **Kathryn Ida Scorgie** in partial fulfilment of the requirements for the degree of **Doctor of Philosophy** in **Special Education**.

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ABSTRACT

Recent research has indicated that despite the increased demands of parenting a child with a disability, many families are able to cope effectively. While much research has focused on stress management and adaptation to crisis situations in families containing children with disabilities, less research has focused on how parents manage life day to day. Therefore, the purpose of this study was to examine life management in families that contain children with a variety of disability characteristics and at a variety of age levels. More specifically, the study examined three aspects of life management: (1) strategies parents/caregivers use to manage life, (2) personal characteristics or attributes that parents/caregivers feel are important for effective life management, and (3) positive transformational outcomes associated with parenting children with disabilities.

The study followed a qualitative/quantitative methodological design. First a series of open-ended, semi-structured interviews were conducted with fifteen parents representing fourteen families containing one or more children with disabilities who were judged by agency personnel to have utilized life management strategies in an effective or constructive manner. A qualitative analysis of the interviews resulted in the formation of nine themes. Then, a fifty-nine item survey instrument, the Life Management Survey, was constructed from the nine themes and their subthemes and mailed to an additional sample of parents of children with disabilities who resided in Alberta. The purposes of the survey were to assess the extent to which a greater number of parents corroborated the findings of the qualitative study and to provide an opportunity to generate additional findings through use of open-form response sections.

The results indicated that parents utilize such life management strategies as positive reframing of their thoughts and attitudes about their circumstances, maintaining a workable balance with respect to personal roles and responsibilities, and utilizing resources to meet personal, child, or family needs. Parents who manage life effectively also perceived such personal traits as patience, flexibility, hopefulness, positive outlook, determination, good problem-solving skills, and strong inner convictions as important for effective life management. Finally, positive transformational outcomes were documented in three areas, personal, relational, and perspectival.

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> "C_____ taught me about interdependence, that who I am is really mediated through another person. . . . I had rebelled at the idea that C_____ had to be dependent. But then I realized he's really interdependent, like we all are" (mother of a child with Down Syndrome).

The opportunity to do research is indeed a privilege, and though I am quick to acknowledge from the start that responsibility for the conclusions reached in this study is entirely my own, I also wish to recognize the contributions of significant others whose insights and scholarship are either directly or indirectly embedded in the pages of this work.

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CHAPTER 1

Introduction

For the majority of parents, the discovery that their child has a disability is traumatic (Krauss, 1993). Parents have described their reactions in such terms as "we were devastated," "we were just absolutely stunned," and "that's when our world really came crashing down" (Greenbaum & Markel, 1990; O'Halloran, 1993; Ray, 1990). While many families manage to deal with the new challenges and adjustments that parenting a child with a disability brings, some families demonstrate exceptionally effective skills at coping. These skills, like these families, are many and varied.

Historically, research has focused on the stresses encountered by families in which a child has a disability (Donovan, 1988). However, as early at 1967 Wolfensberger questioned the usefulness of such a seemingly negative approach to family functioning. As well, parents themselves sometimes resented the implicit assumption of many professionals that living with a child with a disability is by its very nature a negative experience. While the study of how individuals and families manage life successfully cannot be divorced from the stresses they encounter and the physical and social environments in which they live, empirical evidence regarding the manifestation and effects of stress in families containing a child with a disability has been largely inconclusive. Some research indicates that the experience of stress in these families is no greater than for the average family (Frey, Greenberg, &

Fewell, 1989). Other studies suggest that families of children with disabilities experience greater stress than families of children without disabilities (Dyson, 1991; Dyson & Fewell, 1986; Flynt & Wood, 1989; Hamlett, Pellegrini, & Katz, 1992). Several factors may be contributing to these conflicting assessments.

First, a number of research design and methodological deficiencies stemming from use of unequal or no comparison groups, small sample sizes, sampling and professional bias, unidimensional and unimodal measures, and lack of definitional control have been cited as problematic in a portion of the studies (Crnic, Friedrich, & Greenberg, 1983; Dyson, 1991; Glidden, 1993; Henggeler, Watson, Whelan, & Malone, 1990). These methodological errors may mask the true effects of stress in families containing children with special needs and result in either the under-representation or over-representation of stress (Dyson, 1991).

Secondly, other studies have focused on demographic variables such as the socioeconomic status (SES) of the family (Dunst, Trivette, & Cross, 1986), marital status of the parents (Beavers, Hampson, Hulgus, & Beavers, 1986; Trute & Hauch, 1988), level of maternal education (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Saddler, Hielman, & Benjamins, 1993), severity of disability (Dunst et al., 1986; Frey, Fewell, & Vadasy, 1989), age of child (Flynt & Wood, 1989; Trivette & Dunst, 1992), and sex of child (Frey, Fewell, & Vadasy, 1989; Henggeler et al., 1990). While these variables have been shown to affect the levels of family stress in some studies, they are generally unchangeable and offer limited opportunities for intervention. It is therefore important to identify other variables which contribute to the process of adaptation that lie more within the realm of parental or family control.

Thirdly, when comparisons with "normal" families have been made in the literature, difficulty exists in some studies regarding the differentiation between "normal" as it exemplifies the average family confronting a number of problems and difficulties, and "normal" as used to identify an ideal family (Walsh, 1982). As well, there has been a tendency, even by those who are professionally trained to work with persons with disabilities, to accentuate personal and family deficits and negative outcomes, while overlooking family strengths and resources (Barnard, 1994). Thus, outcome measures may be affected by the bias of researchers toward the experience of disability.

Finally, in many of these studies no attempt has been made to differentiate between what Glidden (1993) refers to as demands, stresses, and strain. This differentiation, she asserts, is crucial for the interpretation of research in which testing instruments that "operationalize pathology as stress" (p. 482) are used and, therefore, may imply an overestimation of family maladjustment and stress. Thus, though demands, or potential stressors, are greater for families containing a child with a disability, and the level of these demands often does not seem to change over time (Dyson, 1993), it is erroneous to predict that these families necessarily experience either greater stress or strain than other families (Dyson, 1993; Glidden, 1993; Hamlett et al., 1992; Krause, 1993). Clearly there are other variables which may mitigate the effects of stressors or demands in these families.

A number of more recent studies exploring healthy life adaptation are grounded on the assumption that outcome is dependent not on the mere presence of stress, in and of itself, but rather on how that stress is perceived and managed by the individual or family unit (Aldwin, 1994; Donovan, 1988). The focus in this research has shifted from measuring levels or amounts of stress experienced by individuals or family units, to understanding why some individuals or families seem to be able to function successfully in the presence of inordinate stress while others display signs of serious breakdown. The emphasis has turned from the study of stress to the study of stress management or coping.

What is even more intriguing to some researchers is the assertion by some individuals that the experience of a traumatically stressful event in their lives has led to a positive outcome (Barnard, 1994). They claim to have actually benefitted from, or been "blessed" through their experience with a profoundly difficult life incident. These statements have undermined the implicit assumption that stress is by nature negative in consequence. Aldwin (1994) remarks, "the positive effects of stress do not appear to be anomalous in the general community, and it is time that this fact received more systematic attention in the scientific community" (p. 259).

Many parents of children with a variety of disabilities have asserted through the years that, though the stresses in their lives have often been great, they have not only been able to cope successfully with them, but have experienced positive or beneficial outcomes in spite of, or even in the midst of, the stresses (Badry, McDonald, & LeBlond, 1993; Meyer, 1995; O'Halloran, 1993; Schulz, 1993).

While researchers have been quick to study the various determinants and processes of adaptation and coping in these families, parental statements of positive benefits or outcomes generally have been overlooked. Perhaps it is time for the focus in research on coping and adaptation to be broadened to include transformational outcomes. As Aldwin (1994) concludes, in the end "transformational coping may be the key to positive mental health" (p. 270). As research concerning parents of children with disabilities shifts from a focus on stress to a focus on stress management, these beneficial effects will become more apparent.

Without a doubt the parents of children with disabilities who have been involved in this doctoral study have shaped its progression and outcome in several ways. The original focus of this study was to examine the various strategies parents have used through the years to cope with the stresses of parenting a child with a disability. The intention was to study parents identified as "good copers;" however, this strategy immediately met with disdain from the parents. First, parents in general reacted negatively to the word "coping." One parent summed up this feeling with the remark, "When I use the word 'coping,' those are the days I'm barely holding on. Those are not the days I'm feeling particularly successful." Moreover, questions such as "How are you coping today?" addressed to these parents by extended family members or outsiders were perceived as insensitive and derogatory due to the insinuation inherent in them that life with a child who is disabled must be stressful and negative. This realization, that coping was generally viewed as a negative term to parents, provided the impetus to search for a new word or phrase to use in place of the term coping.

Secondly, it was interesting to note that while parents reacted negatively to the term "coping," they were nonetheless fairly reluctant across the board to identify themselves as "good copers." When initially approached to participate in a study of "good copers," they responded with statements like, "I don't think you really want to talk with me. I'm not a great coper." More than that, they resented the assumption that parents of children with disabilities could conveniently be separated into two distinct categories: good copers and poor copers. They were all well aware of the reality that coping is a complex and multi-faceted construct, and that a parent could be both a "good coper" and a "bad coper" during any given day!

However, when they were asked if they would be willing to talk about the strategies they used to manage their lives successfully as parents of children with disabilities, they responded enthusiastically. Thus, over the span of the first several interviews, the phrase "life management strategies" emerged as a more positive description of how parents felt when they were living successfully with the demands of parenting a child with a disability.

This phrase is not without some mention in the literature. Aldwin (1994) delineates an important difference between coping with stress and managing life. She asserts that coping is what a person or family does in response to a stress that exceeds the person's or family's ability to meet the demands it places on them (see also Donovan, 1988; Masten, 1994). Coping, therefore, involves changing the normal way of functioning in response to a real or perceived stress. On the other hand, when individuals or families have adapted to the crisis situation, they develop new ways of managing their lives, or, if the crisis has abated, they return to their original strategies for managing life. Thus, according to Aldwin, coping strategies are always in response to a real or perceived threat or stress. Management strategies, however, describe those methods which day in and day out, year in and year out, enable the family to run smoothly. So, while the literature continues to examine the process of coping and adjustment to the various stresses parenting a child with a disability brings, this thesis relates to family life as it is lived day to day and, thus, is more concerned with life management than with coping.

A third way in which these parents shaped the development of the thesis was that they, too, began to talk of the positive outcomes embedded in their experiences of parenting children with disabilities. In fact, parents seemed to be describing their experiences as a journey--a journey from the devastation which accompanied the initial diagnosis to a place where they were beginning to discover, and often to their surprise, not only that they were able to manage life effectively, but that they were also being enriched along the way. Thus, the focus of the study broadened to include, not just life management strategies, but transformational outcomes.

Research Questions and Definitions

It seemed at this point as if three distinct components were emerging in the study of effective life management of parents who have children with disabilities. The first relates to life management strategies, that is, those strategies either intentional or unintentional, cognitive or behavioural that are routinely used by individuals, families or family sub-units to manage their daily lives. This component deals with what these parents do to manage life day to day. The focus of the second component is parental characteristics, or the attributes or abilities these parents either possess or view as important for successful management of life to occur. If the first component deals with what these parents do, the second probes what they are like. Finally, the third component considers the experience of transformational outcomes, or those ways in which parents have claimed positive or beneficial outcomes through parenting children who are disabled. This third component examines how parents have been or are being changed.

Therefore, the study was designed to answer the following three questions:

Question 1: What are the various strategies parents of children with a variety of disabilities use to effectively manage life?

Question 2: Is it possible to identify personal attributes or abilities that characterize parents who manage life effectively?

Question 3: Is it possible to extract a common theme or themes describing how parents are transformed through their parenting experiences?

One dilemma which emerged almost immediately was how to identify someone who was "managing life effectively" as the parent of a child with a disability. In other words, how was effective life management to be defined and detected? While the designation had something to do with child outcome, it could not be limited to child progress alone, since many parents successfully manage life with children who have been diagnosed with degenerative disorders. As well, while effective life management had something to do with maintaining a strong marriage, it could not be limited to marital health, since there are many parents who are effectively managing life subsequent to, or even in the midst of, failed marriages (Vohs, 1993). While life management had something to do with overall family well-being, it, too, could not be limited to family health alone due to the fact that even in families that are regarded as dysfunctional, there are often family sub-groups that remain healthy and enable the family to function satisfactorily.

A second dilemma which emerged was the reluctance of parents to identify themselves as effective managers of life. Therefore, it was decided that the judgements of others who were familiar with both the field of disabilities and parents of children with a variety of disabilities would be called upon to assist in locating parents. Parents solicited for inclusion in the study were defined as those who, through the years, have employed strategies for dealing with the various aspects of parenting a child with a disability that have resulted in practical and productive solutions to managing personal and family life.

Therefore, parents identified for inclusion in this study were those judged by others to have utilized life management strategies in an effective or constructive manner. Participants were selected using the criteria of overall satisfactory family adjustment and child well-being and development, considering the nature of the disability (see also Trute & Hauch, 1988, for similar subject selection).

It was interesting to note that while the definitional dilemma existed for the researcher, the identification of parents who managed life effectively seemed fairly straightforward to personnel from agencies representing persons with disabilities. Trute and Hauch (1988), in a similar study of families demonstrating positive adjustment following the births of children with developmental disabilities, reported a 91% concordance rate between families judged to be well adjusted by agency workers and the rankings of paediatricians who were blind to the research purposes. Outcome scores on a number of family functioning instruments corroborated these judgements, thus suggesting that agency personnel are capable of correctly identifying families containing children with disabilities who are functioning effectively. A similar selection technique was utilized for this study.

Finally, while researchers increasingly are examining the ways in which parents of children with disabilities cope with the demands placed on their lives, there has been little attempt to study life management strategies which are prevalent across disability groups and child ages. Researchers have focused on parents of children with specific disabilities such as hearing impairments (Henggeler et al., 1990; Morgan-Redshaw, Wilgosh, & Bibby, 1990), visual impairment (Dote-Kwan & Hughes, 1994; Erin, Rudin, & Njoroge, 1991; Nixon, 1994), mental retardation (Baxter & Cummins, 1992; Beavers et al., 1986; Flynt & Wood, 1989; Rimmerman, 1991), severe disabilities (Rousey, Best, & Blancher, 1992; Todis & Singer, 1991), and attention-deficit hyperactivity disorder (Cunningham, Bremner, & Secord-Gilbert, 1992). Researchers have also focused on specific age groupings, such as preschool children (Dote-Kwan & Hughes, 1994; Mahoney, O'Sullivan, & Robinson, 1992; Redington, Kysela, & McDonald, 1995; Trivette & Dunst, 1992) or adolescent children (Morgan-Redshaw et al., 1990). Few studies of parental coping and adjustment, however, have ranged across both child disability types and child ages. (See Bailey, Blasco, & Simeonsson, 1992, for a study of felt needs of parents across child age and disability types.)

This study, therefore, is designed to present a more comprehensive representation of effective life management of parents of children with a variety of disabilities. Child ages in the qualitative portion of the study range from 3 years to 26 years, and disabilities range from a child with hearing impairment who is gifted, to a child with severe multiple disabilities whose mother described him as being ". . . cortically blind and cortically deaf. . . . He doesn't walk or talk, and I don't know if he knows who we are." The inclusion of questions dealing with life management strategies, parental characteristics, and transformational outcomes is intended to give breadth to the understanding of what it means to manage life effectively as the parent of a child with a disability.

Many parents of children with disabilities have expressed the frustration of having little information on how to begin the journey of parenting a child with a disability, as well as managing their own personal lives, their marriages, their work and their immediate and extended families. The goal of this study is to provide such parents with a road map describing how others are successfully meeting the challenges and have been personally enriched along the way.

Overview of Study

Chapter one has presented an introduction to the study with a rationale for the research, as well as research questions and definitions. Chapter two comprises a review of literature relevant to the study including topics such as family systems theory, coping and adaptation, coping in families of children with disabilities, and transformational outcomes of the coping process. Chapter three describes the qualitative (interview) and quantitative (survey) methodology used to gather and analyze data. Chapter four presents the results of the research, with sections describing the themes which emerged from the qualitative data and the results of the survey instrument. Finally, chapter five provides a discussion of the results and implications of this study for future research.

[Note: To protect the identity of all interview participants and their family members, all designations used to describe or refer to persons involved in the qualitative section of this document are pseudonyms.]

CHAPTER 2

Review of Literature

Selected research relevant to this thesis will be organized under four headings: (1) family systems theory, (2) coping and adaptation in general literature, (3) coping in families containing a child with a disability and (4) transformational outcomes.

Family Systems Theory

It is impossible to explore with insight how parents of children with disabilities manage life successfully without a prior general understanding of family structures and family dynamics. Consequently, this section deals with the following three topics: (1) definitions of families, (2) family operations, and (3) family/environment transactions. First, the common definition of a family will be expanded to incorporate a more complex yet essential meaning unit, that of family identity. Then attention will be given to family operations, or the inner functioning of a family. Finally, consideration will be given to the interaction between the family as a unit and the world at large.

Definitions of Families

Most peoples' notion of a family is essentially that of a nuclear family: one or two parents and their children. Even when the notion of family is expanded beyond this conventional definition, and such expansion is becoming more commonplace, the popular understanding of a family is a group of related people who live together (Hawking & Allen, 1991). However, such an assumption can easily mask the deeper nature and essence of a family.

While it is true that families are usually composed of groups of individuals connected by biological or legal unions, the real ties that bind often are formed at a much deeper level, a level which Handel (1967) referred to as the "psychosocial interior" of the family (p. 1). What Handel was suggesting is that through living together over time family members begin to construct a corporate sense of family identity, that is, they begin to identify the traits that tie them together and define their uniqueness as a family unit.

Family identity is formed in large part through the development of family themes, usually based on shared beliefs or on events in the family's history (Hess & Handel, 1967; McCubbin & McCubbin, 1993; Walsh, 1982). These themes, which sometimes can be quite powerful, serve as organizing principles around which the family is built. Thus, one cannot think of the Kennedys without thinking as well of politics, or the Rockefellers without also considering their financial empire.

Families may identify themselves politically, as conservative or liberal, or socioeconomically, as upper middle class or on welfare. The family theme may incorporate an ancestral or religious motif, or it may reflect the experience of one or more of its members. Reiss (1981) contends that it may only be during times of stress that a family defines itself and consolidates its family themes. Thus, a family containing a child who is disabled may find its identity shaped by the presence of that child (Fewell, 1986a). In such instances family members may refer to their family as a "handicapped family," which may lead to even more refined themes, like being survivors or pioneers in inclusion or new intervention programs (Moeller, 1986).

Hess and Handel's (1967) work was significant due to its emphasis on the role of perception in the formation of family identity. Even though families are joined together through the creation of family themes, they are nonetheless formed of distinct and differing human beings. The key to understanding how family members define their unique interfamilial experiences, they contended, is through understanding the images or perceptions individuals within a family have of themselves as a member of the family and their images or perceptions of each of the other members of the family. For example, one woman may view her children as "dependents who need and reward her," while another "may see them primarily as the group that enslaves her and for whom she wears herself out" (Hess & Handel, 1967, p. 15). It is not so much the presence of the children that influences the mother's view of her circumstances, but her image of them based on her past experiences with them, the meaning she places upon those experiences, and how they interact with her own needs as an individual within the family.

Other researchers have attempted to organize families by family types, or patterns of family organization and responsiveness (Beavers et al., 1986; McCubbin & McCubbin, 1993; Olson, 1991). These researchers contend that family health and outcome in response to a stressful situation can be predicted according to placement of the family within a grid system of family types, ranging from severely dysfunctional (e.g., chaotic, or rigid) to healthy, balanced types. Additional discussion of family types is found in the section of this thesis describing families containing children with disabilities.

Family Operations

Families exist for a purpose, that is, they perform certain services for their members. Turnbull, Summers, and Brotherson (1984) present a framework for conceptualizing what families do and how they operate which is formed of four components: (1) family interactions, (2) family resources, (3) family functions, and (4) family life cycle. These four components will serve as categories for a brief examination of literature dealing with how families operate.

Families operate, first of all, as individual members of the family interact with each other as well as with extended family members. Holden and Ritchie (1988) assert that the rapid growth and development of children demand that parents undergo continuous change, requiring them to be both adaptive and flexible as they balance the needs of their children with their own needs. Furthermore, in most families the members are interconnected to an extent that an event which impacts or changes one person will be felt throughout the family unit (Fewell, 1986a; Seligman, 1991).

Family research has historically focused on the influence parents have on the development of their children. However, recent studies are beginning to switch the emphasis to the effect children can have on their parents and other family members (Ambert, 1992; Sameroff, 1975). Certainly an event as significant as the diagnosis of disability in a child would be expected to have a notable effect on the members of the immediate and perhaps even the extended family (Crnic et al., 1983; Fewell, 1986a; Stagg & Catron, 1986).

Families also operate as family members recognize and utilize their individual resources, such as personal talents, abilities, character traits, previous experiences, intelligence and available time (McCubbin & McCubbin, 1993; Turnbull et al., 1984). The family as a unit also derives resources from family characteristics such as family ethnic or religious beliefs, socioeconomic status, communication patterns, daily routines, and problem solving skills (McCubbin & McCubbin, 1993; Turnbull et al., 1984). While Handel and Hess (1967) view these attributes as critical to the formation of family themes, other researchers see them as resources that both buffer the impact of the stressor and that enable the family to operate day to day and in times of crisis (Aldwin, 1993; Turnbull & Turnbull, 1984; Wikler, 1986). Thus, a family with a child newly diagnosed with a disability is able to draw upon the collective gifts and abilities of its individual members, as well as upon its financial resources and beliefs about issues such as the value of life.

Families function for the purpose of meeting the needs of their members. According to Turnbull et al. (1984) and Fewell (1986a), families are generally perceived as having primary responsibility for ensuring that the economic, educational, health, and daily caretaking needs of their members are met. As well, the family unit is looked upon as the vehicle for securing the emotional attachment of its members and ensuring the socialization of its offspring.

Finally, just as individuals proceed through a life cycle, families operate according to a time frame, as couples progress from being newlyweds, to being parents of children who move through a number of developmental stages, to facing such possible changes as divorce, retirement, aging, and death (Russell, 1979; Walsh, 1982; Wapner, 1993). Family resources and needs may change as both the parents and children move through various life-cycle stages (Dunst et al., 1986b; Mallory, 1995. See Meyer, 1986, for a description of the effects children with disabilities have on fathers during various stages of the life cycle.)

Mallory (1986) suggests that the presence of a child with disabilities may accelerate or delay many of the usual life-cycle markers (see also Mallory, 1995). For example, while parents may face educational intervention earlier, they may experience a delayed or non-existent "empty nest" stage. Similarly, Cook, Lefley, Pickett, and Cohler (1994) suggest that parents of children with severe mental illness face greater childcare burdens during their children's early childhood and late adolescent/early adult periods, with less burden during the period of middle childhood. As well, the focus of burden changes over the child's life cycle from burdens associated with behavioural issues in earlier years to concerns regarding caregiving responsibilities in early adulthood.

In summary, a family operates as a network of unique individuals who interact with one another, who share their personal and collective resources to meet corporeal or societal expectations, and who grow and change over time. If the well-known adage is true that "you can't step into the same river twice," perhaps it is also true that you can never probe the same family twice, for families are diverse, complex and unique. However, families also live in a larger society, and it is the family's relationship to this society that comprises the final topic of this section.

Family/Environment Transactions

People, and the families to which they belong, do not exist in a vacuum; rather, they operate within the structure and confines of the society in which they exist. Researchers such as Bronfenbrenner (1979) and Shea and Bauer (1994) have emphasized a more holistic approach to individual development which regards the person-in-environment system as operating as a unified whole. The underlying assumption of this systems perspective is that changes that occur anywhere within the system, that is, anywhere within the person, the environment, or the interactions that exist between them, affect the system as a whole. Thus, Shea and Bauer (1994) contend, "it is impossible to understand [children with] disabilities without examining the nested contexts (family, classroom, school, community, and society) in which the individual is developing" (p. xxiii).

In a similar way, researchers are beginning to study the family-in-environment system. Perhaps the changing nature of the family has influenced this trend. While families are still viewed by many as having primary responsibilities for meeting the needs of their members, Ambert (1992) contends that with the integration of a growing number of mothers of young children into the workforce in North America, responsibilities for essentials such as socialization and education are increasingly shifting to the community. As well, advances in health care technology resulting in extended life spans for persons with severe or chronic conditions have prompted changes in both educational and social support networks.

Ambert suggests a number of ways society can support parents in their parenting effort. These supports include provision of adequate housing and health care, quality school and out of school care programs, appropriate community and recreational facilities, safe neighbourhoods, and attitudes both that oppose discrimination based on race, gender or disability and that acknowledge the contributions responsible parents make to society. Societies choose to extend or limit these resources based on attitudinal, political or socioeconomic considerations.

There is some question as to whether families with children have larger social networks than childless couples (Ambert, 1992). However, research has demonstrated that families containing children with disabilities often present unique sociological patterns. On the one hand, these parents usually have contact with a greater number of professionals than parents of children without disabilities (Kazak, 1987); yet, at the same time, many of these parents report feelings of isolation from and stigmatization by society (Ambert, 1992; Dunst, Trivette, & Cross, 1986b; Greenbaum & Markel, 1990; Stagg & Catron, 1986; Wikler, 1986). These families also report fewer associations with community organizations and less frequent family outings (Barnett & Boyce, 1995; Stagg & Catron, 1986; Wikler, 1986).

In summary, family systems theory supports the assumption that the family and the environment are so intertwined that changes in one may precipitate changes in the other. Therefore, families containing children whose disabilities require them to modify the way they function internally to meet the needs of their children, often discover that these modifications also impact on their relationships with external structures such as day-care centres, schools, social service agencies, and the workplace. Family members may even go so far as advocating for changes in legislation to guarantee the rights of their children with special needs. At the same time, changes in any of these, or a myriad of other, societal structures may impact on the way in which these families function, requiring yet further family and individual modifications.

Coping and Adaptation

Interest in how people manage stress has been growing steadily during the past several decades. Certainly in North America alone a proliferation of books, videos and seminars on how to cope with stress has been generated. These range from coping with major life crises such as traumatic personal illness or the death of a loved one (Cooper & Faragher, 1992; Davis, 1991; Janoff-Bulman, 1992), to managing the more subtle day to day hassles or microstressors that over time may adversely affect an individual or a family unit (Lazarus & Folkman, 1984; Masten, 1994). The central issues in a large portion of this literature are twofold. First is the issue of individual differences in response to similar stress events. Why are some individuals able to withstand stressful life events while others are overwhelmed by the same events? Second is the issue of resistance against the negative effects of stress. In other words, if specific variables can be found that inoculate certain persons from experiencing the devastating effects of stress, can these "antigens" be instilled in other people?

Thus, interest has shifted from the study of stress to the study of coping, or how individuals or families manage stress. Because the literature on coping in general covers such a vast range of topics across domains including medicine, psychology, biology, sociology, anthropology, education, and family studies, this section will present only a brief summary of the literature especially pertinent to this thesis. The topics will be arranged as follows: (1) factors fostering variability in personal and family coping, and (2) determinants of coping, such as resilience, appraisal, resources and social supports.

Factors Fostering Variability in Personal and Family Coping

The study of coping in families in general has been fragmented by the diversity of methods and perspectives brought to bear on the subject. While some researchers have delineated the characteristics of people or families who are "good copers," others have examined coping as a process from a state of crisis to one of outcome, or adaptation. Nonetheless, as a result of this research several important variables which have influenced coping have emerged.

First, coping is person-specific. What may be regarded by one person as positive coping, or a solution to stress, may be completely intolerable to another (Aldwin, 1994; Cooper & Faragher, 1992; McCord, 1994). For example, one mother may cope with the increased demands of returning to full-time employment by reducing her expectations that her house always be spotless. For another, the sight of dust on the coffee table day after day may lead to increased feelings of stress rather than coping. Clearly what "works" for one person does not always "work" for another (Willoughby & Glidden, 1995).

Furthermore, individuals may perceive life events differently (Janoff-Bulman, 1992; Moos & Schaeffer, 1986). Certain events, such as a personal illness, which might be perceived as a threat or adversity to one person or family unit, may be interpreted as a challenge or an opportunity for growth or achievement to another (Gordon & Song, 1994). There is some indication that socioeconomically disadvantaged families view the presence of a child with a disability as less threatening than their middle- or upper-class counterparts (Wikler, 1986). Thus, perception of impact can serve either as a buffer against the negative effects of a stressor (Ireys, Werthamer-Larsson, Kolodner, & Gross, 1994) or as a reinforcer of the magnitude of the stressor (Janoff-Bulman, 1992).

Second, coping is context-specific. In other words, individuals bring into every environment or context in which they operate certain associations or meanings based on past experiences in that environment (Aldwin, 1994). Thus, one may encounter wide divergence in coping within the same individual; for example, the lawyer who, while he or she may exhibit fearless confidence in the court chamber, nevertheless may fall apart in the dental chair.

Similarly, coping is context-specific because it is influenced by the norms of the society in which one lives (Mallory, 1995; McCord, 1994). What may be considered an appropriate way of dealing with stress in one culture, such as placement of an infant or young child in a daycare setting, may be viewed as undesirable or even unacceptable in another culture (Ambert, 1992; McCubbin & McCubbin, 1993). Furthermore, when social changes do occur, such as the deinstitutionalization of persons with disabilities resulting in their inclusion within the community, the educational system and the workforce, individuals and families often must work out new ways of coping (Aldwin, 1994). Thus, research on coping and adaptation must not overlook the influence of contextualization on outcome.

Third, coping may vary with time (Gordon & Song, 1994; Hobfoll & Spielberger, 1992; Koop & Keating, 1990). How a parent or family deals with the demands of a chronically ill child may change from one day to the next or from one year to the next. Because people and families grow and change, the collective resources and abilities of the individual members of the family as a unit may also change over time (Dunst, Trivette, & Cross, 1986b; Mallory, 1995).

Fourth, coping is influenced by additional internal or external family variables (Barnard, 1994; Gordon & Song, 1994; McCubbin & McCubbin, 1993). Events such as personal illnesses, a move to a new location, or the death of a grandparent may force the family to reexamine how it functions and copes with a stressful situation. Job loss may place a family in financial crisis necessitating the entry of a second parent into the workforce, thus changing the way a family operates (Hanson & Carta, 1995).

Finally, coping exists along a continuum. Therefore, while one might examine coping in terms of degrees of coping, it is impossible to establish a distinct line of demarcation that sets apart "good copers" from "poor copers" (Eisner, 1994). In conclusion, coping in individuals and families is difficult to study because coping is influenced by many factors which introduce variability in measures of coping. Nonetheless, recurring determinants of coping have been investigated. A number of these determinants will be examined in the next section.

Determinants of Coping

Coping has been defined as "the use of strategies for dealing with actual or anticipated problems and their attendant negative emotions" (Aldwin, 1994, p. 107). When encountering a stressful situation, individuals may respond by trying to change aspects of the problem itself (problem-focused coping) or by reducing negative emotions resulting from the stress (emotion-focused coping) (Lazarus & Folkman, 1984). Coping, therefore, is a complex process involving the interchange of a number of equally complex variables. Several of these determinants have received extensive coverage in the literature and will be examined in this section. They are: (a) general resilience, (b) appraisal, and (c) resources and social supports. Problem solving skills, also frequently mentioned, will be examined within the context of the other three determinants.

General resilience. Medical researchers have long known that simply exposing a person to germs does not always result in his or her physical illness. Clearly, some individuals seem more resistant than others to the detrimental effects of viruses or bacteria. Similarly, psychologists have also observed that exposure to stress is not always associated with negative outcome. In fact, Gordon and Song (1994) contend that "even with the most severe stressors and the most glaring adversities, it is unusual for more than one half of observed individuals to succumb to psychological or social dysfunction" (p. 29). Some individuals seem to have defences against the negative effects of stress. A number of recent studies have attempted to delineate the personal and environmental characteristics or qualities that facilitate personal resilience in the presence of stress (Barnard, 1994; Wang & Gordon, 1994).

Masten (1994) refers to resilience as "a pattern over time characterized by good eventual adaptation despite developmental risk, acute stressors or chronic adversities" (p. 5). She asserts that each individual possesses both risk factors (e.g., poverty, single parent family status) and assets (e.g., high IQ, nurturing familial environment) which influence and may even determine overall personal adaptation. While acknowledging these traits, Freiberg (1994) embraces a more active orientation, defining resilience as "the ability to become proactive rather than reactive" (p. 152) in response to a stressful situation.

Gordon and Song (1994) have specified a number of variables contributing to resilience in children who have excelled in spite of living in poverty. These include the presence of significant others, support for development and learning, a sense of community, positive role models, innate and developed ability, and personality (p. 32). In a similar vein, Freiberg (1994) cited a study done in 1991 by Benard regarding children who succeeded in school in spite of environmental disadvantage. These children exhibited four protective traits: social competence, strong problem solving skills, personal autonomy, and future-oriented goals. Like Gordon and Song, Benard also noted that foundational to each child's success was the presence of at least one supportive person.

Herrenkohl, Herrenkohl, and Egolf (1994) noted that resilient children show both a positive responsiveness to supportive influences in their environments and an ability to distance themselves from dysfunctional family situations. Brooks (1994), on the other hand, emphasized the importance of self-esteem, optimism, and personal control in resilient children.

Studies of resilience in adults show similar outcome variables. In an analysis of three groups of resilient adults, Beardslee (1989) noted that one trait they held in common was the ability to arrive at a theoretical understanding of their unique situation and act in accordance with that information. Thus, he acknowledged that resilient individuals are able to engage in effective, action oriented approaches to problem solving. Finally, in a meta-analysis of research pertaining to resilient adults, Barnard (1994) suggested that the correlates of resilience could be separated into two categories: individual and family. Individual correlates include skill in building close relationships both within and outside of the family, the ability to give a positive interpretation to life events, having an internal locus of control, and absence of serious stress during adolescence. Family correlates include maintaining family rituals, facility in family problem solving, a positive maternal relationship, and the presence of a supportive mate.

However, research has demonstrated that any one of these variables has been unable to significantly influence an outcome in and of itself. Gordon and Song (1994) argue that ". . . these factors and others interact dialectically and reciprocally to accommodate and influence each other" (p. 32). Consequently, studies of resilience are focusing less on independent individual or environmental traits and more on the interrelationship of and interaction between a multitude of variables (Herrenkohl et al., 1994; Rigsby, 1994; Wang, Haertel, & Walberg, 1994).

Gordon and Song (1994) attribute overall resilience to the interaction between three variables: personal characteristics, environmental characteristics, and situational constraints (p. 32-33). Personal characteristics include both relatively fixed attributes such as socioeconomic status, ethnicity, language, and IQ, as well as constitutional attributes such as self-concept, motivation, temperament, values and beliefs, social competence, and personal health (p. 33). Environmental characteristics consist of other persons and objects in the environment that may influence individual outcome positively or negatively. Situational constraints are those variables which facilitate or impede the interaction between the person and the environment, such as having opportunities, being in the right place at the right time (or the wrong place at the wrong time), external expectations to succeed or fail, and societal values. By understanding the composition of these variables and the social processes in which they function, it might be possible to create for disadvantaged individuals conditions within the environment that facilitate resilience (Bartelt, 1994; Rigsby, 1994).

Taylor (1994) cautions of the dangers of expecting "extraordinary outcomes from all individuals facing obstacles to development" (p. 128). Because individuals, the environments in which they live, and their interactions within those environments are so complex and so unique, it may be impossible to predict with accuracy what variables in combination will produce success for any one individual. Instead, Taylor calls for changes at the societal level, with more global efforts to modify environmental variables, such as poverty, that contribute to poor outcomes (see also Hanson & Carta, 1995).

McCord (1994) also cautions researchers of the importance of maintaining a clear differentiation between personal prevention factors, or those factors that keep the stress event from occurring, and personal protective factors, or those factors that protect an individual from experiencing the negative effects of a stress that has already occurred. Thus, she proposes differentiation between risk prevention strategies and risk protective strategies.

For parents who have children with disabilities such variables as parental IQ, socioeconomic status, and marital harmony may be thought of as protective factors, and positive life management strategies might be viewed as prevention factors. In other words, while sufficient financial resources and a strong marriage relationship may protect a family from negative outcomes once stress has occurred, good life management strategies enable the family to reduce as much as possible the likelihood of experiencing additional stresses on a day to day basis.

In summary, though researchers have been trying to identify those variables that are present in people who exhibit resilience, and a number of variables have been identified, no single variable or set of variables has emerged as dominant. Rather, researchers are beginning to study the interaction of the individual or family and the environment, also taking into account unique situational factors that influence that interaction. As well, recent studies are demonstrating that for some individuals positive outcomes may be differentially distributed across life domains or time periods. For example, positive behaviours may typify one domain, such as the work environment, while dysfunctional behaviour may characterize another domain, such as interpersonal relationships (Herrenkohl et al., 1994).

Appraisal. Exposure to threatening life events may do more than change how an individual or family interacts and functions. The experience of a stressful event may also challenge the basic assumptions and foundational beliefs that an individual or family has about the world and how it operates (Garcia, 1994; Janoff-Bulman, 1992). Meichenbaum and Fitzpatrick (1993) enumerate five beliefs that may be challenged or invalidated through the experience of a stressful event: "(1) the belief in one's own invulnerability . . . , (2) the belief that events are predictable, controllable and just, (3) the belief that the world is benign and benevolent, (4) the belief that life is meaningful, and (5) the belief in the worth of oneself" (p. 708).

Meichenbaum and Fitzpatrick contend that "individuals do not respond to events in and of themselves, but they respond to their interpretation of these events and to their perceived implications of these events" (p. 707). In fact, these interpretations, or appraisals, of the stress event and its impact on one's life, may well be foundational to understanding individual differences in response to similar stress events (Ireys et al., 1994; Lazarus, 1993).

McCubbin and McCubbin (1993) describe three levels of appraisal that may influence how members of a family judge the impact of a stressful event. The first involves an immediate judgement by the family members of the stressful event itself, especially focusing on characteristics of the event such as its intensity and expected duration. The second level of appraisal focuses on the family's perception of its own ability to meet the demands created by the stressful event, resulting in attributions of adequacy or inadequacy. The third level deals with the meanings the family as a unit attaches to the stress event. Koop and Keating (1990), however, contend that because these distinctions are really inseparable during the appraisal process, it is unnecessary to think of separate levels of appraisal.

It has been argued that an individual's thoughts, feelings and perceptions about an event are more significant in determining outcome than the actual factors present in the event itself (Frey, Greenberg, & Fewell, 1989; Gordon & Song, 1994; Wikler, 1986). However, interactionists would maintain that appraisal is "a function of both the person and the situation" (Janoff-Bulman, 1992, p. 53). Meichenbaum and Fitzpatrick (1993) assert that recovery from a threatening stress event is predicated on the ability of the individual or family to adapt in a manner which restores faith in the goodness and inherent value of self and of life. This is accomplished, they contend, through the construction of narratives, or stories, by individuals or families that enables them to interpret the threatening life event in a positive way.

Individuals or families who experience negative outcomes often construct narratives that emphasize themes such as victimization, unfavourable comparisons with others or with life prior to the stress event, blame, personal vulnerability, and meaninglessness (Meichenbaum & Fitzpatrick, 1993, p. 711). In contrast, individuals or families that exhibit positive outcomes construct narratives that emphasize themes such as personal control, positive meaning, beneficial effects, self-esteem, and valuing personal problem-solving endeavours. Interventions aimed at assisting family members to replace negative statements with positive ones are beginning to be reported in the literature (Barnard, 1994; Frey, Greenberg, & Fewell, 1989; Kirkham, Schilling, Norelius, & Schinke, 1986; Schilling, Gilchrist, & Schinke, 1984).

Antonovsky (1993) emphasized the importance of maintaining a sense of coherence or integration between the events of one's life and one's view of the world at large. Individuals with a strong sense of coherence see the world as consistent and organized, as opposed to chaotic and unorganized. In order for individuals to maintain a sense of coherence in the midst of stressful events, he argues, they must be able to do three things: (1) comprehend the problem at hand, (2) have the resources available to manage the problem, and (3) derive some kind of meaning from the encounter with the stressful event. Thus, the three factors, comprehensibility, manageability, and meaningfulness are important components of successful coping.

While a family's initial appraisal may operate as a buffer against the negative effects of stress (Hamlett et al., 1992; Wikler, 1986), individuals or families may cope with stressful events by changing or reframing their appraisal of the situation (Barnard, 1994; Frey, Greenberg, & Fewell, 1989; Koop & Keating, 1990). Through the process of reframing, family members are able to change both their emotions toward and the meanings they associate with an event, and to generate new possibilities and solutions that promote healthy living (Barnard, 1994; Moos & Schaeffer, 1984).

Turnbull and Turnbull (1993) use the phrase "cognitive coping" to describe a way of thinking about one's circumstances that results in enhanced self-esteem, feelings of mastery or control, and positive meanings associated with the event (p. ix). Families that utilize cognitive coping strategies typically focus on the positive or humorous side of their circumstances, note favourable ways in which their circumstances compare with those of others, and believe there is meaning or purpose in the things that happen to them. These themes originated in a study which surveyed the reactions of women to the diagnosis of cancer. Taylor (1983) noted that women who cope well generally tend to (1) search for significance or meaning in their diagnoses, (2) engage in efforts to feel positive about themselves, and (3) make active attempts to gain control over their treatment strategies and their lives in general. (See also Cooper & Faragher, 1992, for similar findings.)

Stovya and Carlson (1993) argue that perception of control, or what they call "controllability," is foundational to stress management or coping (p. 749). It has been suggested that positive appraisal produces feelings of control (Miller, Gordon, Daniele, & Diller, 1992). Of particular importance is the individual's or family's "locus of control," or belief about their ability to influence outcome. Persons who exhibit an internal locus of control attribute success to their own abilities to manage a situation. Conversely, those who manifest external locus of control believe that their outcome is primarily determined by fate or luck or other variables over which they have no regulation. Folkman et al. (1991) allege that to gain a sense of control over a stress event individuals (or families) must first be able to discern between the changeable and the unchangeable aspects of their situation. Furthermore, Beardslee (1989) asserts that individuals who adapt in spite of risk tend to develop realistic expectations of their situations and set goals that are within their capacity to attain.

Thus, in short, an individual's or family's appraisal of a stressful event is influenced by several elements, such as comprehending the difficulty of the stress situation, ascertaining meaning generated by the event, sustaining or enhancing self-esteem in the midst of the event, and maintaining control over the event and its outcome. Aldwin has remarked that, rather than associating stress with negative outcomes, researchers might more accurately view stress as "having an activating effect" (p. 23). Similarly, it might be argued that appraisal has an activating effect, which sets in motion expectations of either a positive or a negative outcome, and influences the ability to cope or adapt. Thus, how a family containing a child with a disability initially appraises and subsequently reappraises its circumstances and functioning may have a strong positive or adverse effect on management outcome.

Resources and Social Supports. Earlier it was noted that in times of stress family members may pool and utilize their individual and collective resources to cope with the demands of a stressor. These resources include individual, marital, and familial characteristics, extended family, friends and neighbours, community organizations, and professionals (Fredrich et al., 1985; McCubbin & McCubbin; 1993; Schilling et al., 1984; Wikler, 1986).

Beneficial social supports generally meet the following five requirements: (1) they provide the family with adequate emotional support, (2) they enhance family esteem, (3) they encourage a sense of belonging to a larger community, (4) they assist the family in assessing their strengths and weaknesses, and (5) they engender a feeling of having contributed positively to others (Cobb, 1976; cited in McCubbin & McCubbin, 1993. See also Stagg & Catron, 1986, for a similar examination of social network supports of parents of children with disabilities). Resources, such as financial or housekeeping assistance, babysitting or respite services, and adequate information, may also be necessary in times of stress

(Mallory, 1986).

Hobfoll (1989) maintained that events are stressful when they either threaten the family with a loss of valued resources or hinder the family's ability to rebound after a period of resource depletion. Therefore, he professed that resources are conserved in a system of checks and balances, and stress is measured by the perceived or real extent of resource expenditure. However, others argue that existing resources may buffer a family against the negative effects of a stressor (Cooper & Faragher, 1992; Parks, Lenz, & Jenkins, 1992) or that coping, rather than depleting resources, may ultimately result in the creation of new resources (Aldwin, 1994).

Hobfall and Vaux (1993) contend that people do not passively plug resources into their areas of need. Rather, they actively shape resources to fit their unique family needs. Therefore, Hobfoll and Spielberger (1992) differentiate between resources that fit and "fitting resources" (p. 103). Resources that fit, they contend, are not concerned as much with whether the resource is positively or negatively valued, but rather with whether the resource effectively meets the demand. "Fitting resources" implies, however, that the individual or family actively adapts the resource to meet the unique need.

Two aspects of social support that have received attention in the literature are support quality and support density. High quality support is more likely found among family members and close friends who generally are more aware of a need, more motivated to provide assistance, and more likely to regard the self-esteem of the individual or family as important (Hobfall & Vaux, 1993; Wikler, 1986). It is not surprising, then, that quality of support provided by husbands leads to more positive outcomes in mothers of newborn infants (Parks et al., 1992) and children with mental retardation (Friedrich et al., 1985). At the same time, it must be kept in mind that family members whose views or values vary widely from that of the person experiencing stress may actively contribute to rather than assist in alleviating stress. Support density is identified by the composition and structure of the support network. Research regarding support density is generally inconclusive. While some studies have shown it is better to have a few high quality resources than a larger number of minimally supportive ones (Friedrich et al., 1985), families often fare better when resources fulfil multiple needs (Parks et al., 1992; Wikler, 1986). Parents of children with disabilities often have small, dense social networks, and rely on a few close family members and friends for the bulk of their support (Kazak, 1987).

Thus, one might compare resources to money in the bank. Families who have a rich portfolio of resources, both in quality and in diversity, will be better equipped to meet needs across a number of domains than families with fewer and inferior resources.

However, the presence and availability of resources does not always ensure positive outcome (Koop & Keating, 1990). In a study of mothers of high risk infants placed in neonatal intensive care units, Affleck, Tennen, Rowe, Rosher, and Walker (1989) found that mothers who participated in a supported training program after indicating that they did not need or want it felt less maternal control, competence and self-esteem at completion of the program. As well, in a study of caregivers of children with HIV infection, Lesar, Gerber, and Semmel (1995) found no relationship between measures of social support and family adaptation, possibly due to the reluctance of caregivers to share the diagnosis of HIV with others. Therefore, perception of both the need for and the quality of the resource can affect its usefulness to an individual or family unit (Donovan, 1988; Hamlett et al., 1992). As well, the kind and amount of support needed may change over time (Dunst, Trivette, & Cross, 1986b).

Coping in Families of Children with Disabilities

A review of current literature describing the various components of coping in families containing a child with a disability is summarized in Table 1. The findings from these studies as well as from an examination of several of the methodological approaches to the study of families containing children with disabilities are classified using four categories: (1) family variables, (2) parent variables, (3) child variables, and (4) external variables.

Family Variables

Researchers have delineated a number of family characteristics that influence the family's ability to cope successfully with the unique needs of a child with

Table 1. A Review of Recent Literature on Stress and Coping in Families Containing Children with Disabilities

Study	Subjects	Disability	Methodology	Coping Variable	Findings
1. Barnett & Boyce (1995)	237 mothers 134 fathers of children with Down syndrome Control - 216 mothers & 174 fathers	Down syndrome	Telephone interviews - 4 interviews with primary respondant, 2 interviews with secondary caregiver Time diaries - 24 hour recall of time spent (over telephone) Scales of Independent Behaviours (administered by phone)	Use of time	- mothers of children with Down syndrome worked outside the home 7 hours less per week and worked in the home 9 hours more per week than mothers of children without disabilities. - fathers of children with Down syndrome devoted 4 hours more per week to child care and 2 hours less per week to social activities than fathers of children without disabilities. - there was no difference between the two groups of parents regarding time spent on personal care, sleep, passive leisure, shopping, and educational activities.
2. Baxter & Cummins (1992)	parents of children: a) 3-5 yrs. b) 10-12 yrs. c) 17-19 yrs.	moderately/ severely intellectually impaired and multiply disabled	Interviews - one or both parents Parent self-report questionnaire (duration of study - 7 years)	Coping with stigmatizing social attitudes. Parental verbalizing of concerns	- parental stress caused by stigmatizing social attitudes tends to remain stable over time. - verbalizing was generally more effective in reducing stress than either controlled anger or disassociation (avoidance).

Study	Subjects	Disability	Methodology	Coping Variable	Findings
3. Bailey, Blasco, & Simeonsson (1992)	422 parents or caregivers of children aged 3 mons. to 14 yrs.	a variety of disabilities including motor impairment, visual impairment, mental retardation, hearing impairment, and developmental delay	Family Needs Survey	Expressed needs of mothers and fathers	- greatest needs of parents were informational: - regarding present and future services - regarding how best to teach child - regarding child's disability - other needs: - meeting/reading about other parents/families - time for self (twice as prevalent for mothers) - mothers and fathers generally demonstrated the same pattern and frequency of needs.
4. Barakat & Linney (1992)	57 families of children aged 6 - 11.	29 children with spina bifida 28 control (non-disabled)	Interviews with parents and children Videotaped play interactions Vineland Adapted Behavior Scale Brief Symptom Inventory Child Behavior Checklist Peabody Picture Vocabulary Test - R Pictorial Scale of Perceived Competence and Social Acceptance for Young Children Severity of Handicap Index	Social Support Maternal Adjustment Child Adjustment	- maternal psychological adjustment related to support from other family members, availability of support network, and satisfaction with support. - maternal adaptation may be associated with child intellectual level and SES - severity of disability not related to adjustment of mother or child.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
5. Cunningham, Bremner & Secord-Gilbert (1993)	101 families of pre-school and school age children	at-risk for attention-deficit hyperactivity disorder (ADHD)	Parent training model Videos utilized to expose parenting errors and promote problem-solving strategies. Small group brainstorming (duration - 2 sessions of 8 weeks with follow-up)	Problem solving skills Family Roles Parental Communication	- parent training programs are effective for teaching behaviour management skills and enhancing parental competence and control.
6. Donovan (1988)	72 mothers	36 children with autism 36 children with mental retardation	QRS-R Locke-Wallace Marital Adjustment Scale CHIP-D	Coping styles Perception of stress	- mothers of autistic children reported higher stress, more parent and family problems, more difficulty with child behaviour, and more limited child abilities. - no difference in quality of maternal marital adjustment between 2 groups - mothers of older autistic children reported greater stress.
7. Dyson (1991, 1993)	55 families of children age 7 or under matched with 55 normal families by SES and family structure (74 total families at post-test) (participants were mostly mothers)	mental retardation, speech disorders, learning disabilities and developmental delays	Questionnaires: Questionnaire on Resources & Stress (QRS-F) Family Environment Scale (initial study with follow-up data collected after 2 years)	Cohesion	- families with disabled children have more stress but do not differ in measure of family health. -stress remains constant over time. - more stress associated with caretaking demands, parent pessimism and negative perception of child limitations. - cohesive and supportive families mediate stress.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
8. Failla & Jones (1991)	57 mothers of children age 6 and under	moderate developmental delay	Questionnaires: Family Hardiness Index Family Stress Index Norbeck Social Support Questionnaire Family Coping - Coherence Coping Health Inventory for Parents (CHIP) Feetham Family Functioning Survey (duration - 1 hour to complete questionnaires)	Family Hardiness	- families with high levels of hardiness perceive stressful events as challenge, use more coping strategies, and have stronger family relationships. - older mothers with more children were less satisfied with family functioning.
9. Flynt & Wood (1989)	90 mothers of children: a) 6-9 yrs. b) 12-15 yrs. c) 18-21 yrs.	moderately mentally retarded	Questionnaires: QRS-F CHIP (administered by telephone interview)	Coping of Mothers	- black mothers showed less stress due to greater reliance on intrafamilial supports. - older mothers reported lower stress. - age of child, no effect. - married mothers employ different coping strategies than single mothers. - SES had no affect on stress but low SES mothers used fewer coping strategies.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
10. Frey, Fewell & Vadasy (1989)	48 parents (mothers/fathers) of children, 8 months to 12 yrs.	mild/moderate/ severe intellectual & physical impairment	Questionnaires: Parent Problem-Solving Assessment Scale Family Support Scale Quantity & Satisfaction with Social Support Networks The Religion Scale Daily Parenting Hassles QRS-F Family Relationship Inventory Home Quality Rating Scale Beck Depression Inventory (Pretest-Post-test after 2 years)	Parent Adjustment to child Family Adjustment Personal Adjustment	- child communication ability predicted parent adjustment. - sex of child (girl) predicted positive parent adjustment. - satisfaction with social support predicted adjustment. - no change in stress level over 2 yrs. - fathers perceptions at pre-test predicted mothers perceptions and child social competence at post-test.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
11. Frey, Greenberg, & Fewell (1989)	48 mothers 48 fathers	Down syndrome (60%) Cerebral palsy (16.5%) Other disabilities (23.5%)	Daily Parenting Hassles QRS-F Family Relationship Inventory Marital Adjustment Scale Family Support Scale Brief Symptom Inventory Revised Ways of Coping Checklist Belief in Personal Control Scale Comparative Appraisal Scale Vineland Adaptive Behavior Scale Home Quality Rating Scale	Family Adjustment Coping Styles Social Support Network	- severity of disability related to increased stress - child communication skill related to increased stress, especially for fathers - parent beliefs and perceptions about disability and impact related strongly to parent outcomes. - positive parental comparisons to other situations (i.e., feeling that they were better off) associated with positive outcomes - perception of ability to control situation is related to positive outcome
12. Gallimore, Weisner, Bernheimer, Guthrie & Nihira (1993)	102 Euro-American families with children, 32-55 mos. - mainly middle class, 2-parent	developmental delays of unknown or uncertain cause	Interviews: 2-3 hours semi-structured, primarily with mothers. Case Materials Ratings on 10 ecocultural domains (low-high) (single interview)	Family Accommodation	- no difference in accommodation from normal families. - accommodations were linked to impact of disability on family routines. - areas of accommodation include use of time, scheduling, role divisions, parent vocation and child care. - income, parent education, SES no influence.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
13. Hancock, Wilgosh & McDonald (1990)	6 mothers (white, middle class, married)	visual impairment (legal blindness)	Interviews: Semi-structured (45 mins. - 2 hrs.) Telephone follow-up (1 interview - 1 follow-up)	Maternal personality Child attitude Social Supports	- maternal inner strength related to positive coping. - positive child attitude and evidence of progress related to positive coping. - parent support groups assisted adjustment. - religious beliefs and assistance from other family members cited as variables related to coping. - dealing with professionals, educational needs, stigmatizing social attitudes and time factors were stressful.
14. Henggeler, Watson, Whelan & Malone (1990)	parents of 47 school age children (mixed racial and marital status, lower middle class) compared with parents of 57 hearing students	hearing impairment (mild - profound)	SCL-90-R (Derogatis) Global Severity Scale Marital Adjustment and Prediction Test - Short (MAS) QRS-F FACES-II (1 data collection)	Adaptation Family Cohesion	- parents of hearing impaired similar to control population on measures of adaptation and marital satisfaction. - length of time since diagnosis had no effect on adaptation and marital satisfaction. - family cohesion scores predicted low maternal distress and high marital satisfaction. - gender of child (female) predicted reduced stress. - degree of disability related to maternal satisfaction measures.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
15. Krauss (1993)	121 mothers & fathers of toddlers	disabilities including Down Syndrome, motor impairment and uncertain etiology	Interview with mother during home visit Questionnaires: Child Assessment Questionnaire Parenting Stress Index Child Improvement Locus of Control Scales Parent Support Scales Family Adaptability and Cohesion Evaluation (1 data collection)	Cohesion Social Support Adaptability Appraisal	- no correlation between type of disability, locus of control, size of support network, family type and stress. - parents of girls report higher satisfaction with social supports. - mother stress related to parenting variables, health and relationship to spouse. - father stress related to child variables. - mother ranked family higher in cohesion and adaptability.
16. Mahoney, O'Sullivan & Robinson (1992)	503 mothers of children age 6 and under	moderate to profound handicaps including Down Syndrome, cerebral palsy and sensory impairment	Questionnaire: Family Environment Scale (1 data collection)	Family Environments Social Supports Cohesion	- families with disabled children participated less in recreational activities, and have stronger moral/religious orientation. - no relationship between severity of disability and family environment. - mothers' unmet needs for support create distress. - interfamilial support mediates stress.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
17. Miller, Gordon, Daniele, & Diller (1992)	132 mothers	69 physically disabled children 63 nondisabled children	Family Support Scale Ways of Coping Questionnaire The Appraisal Components Brief Symptom Inventory The Sickness Impact Profile	Stress Appraisal Coping	- mothers of children with disabilities demonstrated greater psychological stress overall. - emotion-focused coping associated with hightened stress. - problem-focused coping associated with reduced stress. - limited information about child disability associated with increased stress. - positive appraisal is related to maternal adjustment. - problem solving ability associated with less stress.
18. Rimmerman (1991)	24 Jewish mothers of pre-school children	severe mental retardation	Questionnaires: Rotter's Locus of Control Scale Interpersonal Support Evaluation List QRS-F (1 data collection)	Maternal Focus on Control Social Supports	- locus of control and perception of social support act as buffers against maternal pessimism. - maternal morale is strong factor in mediating stress.
19. Rousey, Best & Blancher (1992)	93 parents (mothers/fathers) (white/middle class)	severe developmental delay	Questionnaires: QRS-F (administered during home visit) (1 data collection)	Appraisal	- mothers reported more pessimism than fathers. Pessimism highly correlated with child characteristics. - high degree of child impairment correlated with lower marital adjustment in fathers. - gender of parent no effect on measures of stress and coping.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
20. Saddler, Hillman & Benjamins (1993)	139 parents (mothers and fathers)	48 children with cerebral palsy 46 children with diabetes 45 children with no disabilities	QRS-F Family Functioning Index Locke-Wallace Marital Adjustment Inventory Norbeck Social Support Questionnaire Religion Scale	Family Functioning	- positive correlation between marital adjustment and family functioning. - higher SES associated with better child outcome measures. - maternal education level associated with better child outcome measures. - mothers and fathers perceptions of family functioning were similar. - no difference in family functioning between disabled and nondisabled families. - visibility of disability not related to family functioning.
21. Todis & Singer (1991)	6 families of multiple adoptive children with disabilities	severe developmental or multiple disabilities (Down Syndrome, cerebral palsy, sensory impairment, developmental disabilities)	Participant Observation (3 hour duration) Interviews (semi-structured) (5 months data collection)	Household Organizational Strategies Contact with other parents Social Supports Time Variables Parent Appraisal	- household management not found stressful. - interactions with school, medical personnel and other professionals ranked extremely stressful. - concern about future stressful. - adolescent behaviour problems stressful.
22. Trivette & Dunst (1992)	88 mothers of pre-schoolers	developmentally at-risk, mental retardation & physical disabilities	Questionnaires: Family Support Scale Parent Role Scale QRS-F Parent-Child Play Scale	Role Division Social Support	- no relationship between child age or disability and role satisfaction. - married mothers seek inter and intrafamilial support. - single mothers seek more agency support. - role satisfaction not related to maternal employment.

Study	Subjects	Disability	Methodology	Coping Variable	Findings
23. Trute & Hauch (1988)	36 families (mothers/fathers) of pre-schoolers judged to have positive adjustment	developmental delay	Interviews: (2 hrs) Family Assessment Measures - III Dyadic Adjustment Scale Texas Social Behaviour Inventory Beck Depression Inventory Colorado Child Temperament Inventory Perceived Social Support from Family Scale	Family Adaptation Informal Networks Marital Relationship	- positive adaptation unrelated to child age or temperament, severity of disability, or family income. - 2-parent families with few children were at advantage. - family function affected by income. - marital relationship correlated with positive family functioning.
24. Willoughby & Glidden (1995)	48 married couples	children diagnosed with or at risk for developmental disability	Interviews Locke-Wallace Marital Adjustment Test Child IQ	Marital Satisfaction	- fathers generally participated in less child care activities than mothers. - father participation correlated with marital satisfaction for both mothers and fathers. - income level predicted marital satisfaction for fathers. - no correlation between working mothers and assistance in child care responsibilities by fathers.

disabilities. Although there is overlap between many of these variables, the underlying commonality is that each describes coping as it relates to the family as an aggregate unit. This section will examine the following topics: (1) family adaptation, (2) family cohesion, (3) family hardiness, (4) family creativity, (5) family roles and routines, (6) family composition and (7) other family variables.

Family Adaptation. Adaptation (also known as family flexibility or accommodation) refers to the ability of the family to change both during crisis and over time in response to a stress (Martin & Cole, 1993; Olson, 1991; Redington et al., 1995; see also Gallimore et al., 1993). These changes may occur in the power structure or role relationships within the family system or in the rules and values that define how the family operates (Olson, 1991). Olson's Three-dimensional Circumplex Model of family functioning (1991) depicts family adaptation (which was renamed "flexibility" in the 1991 update of the model) as a curvilinear relationship. Families that demonstrate too little flexibility, or adaptation, are categorized as extremely authoritarian or rigid, whereas families that are overly flexible often lack leadership and are categorized as chaotic. Olson maintains that healthy families strive to sustain a balance between the two extremes of flexibility which results in shared leadership within the marital/family system (see also Russell, 1979). Other researchers view adaptation (and cohesion) as linear constructs and, therefore, correlate high levels of these two measures with positive family or personal coping (see Henggeler et al., 1990).

In a study of the adaptability of families containing children with developmentally delayed toddlers, Krauss (1993) reported that mothers indicated higher levels of adaptability within the family than fathers, and that families with lower, or as Olson (1991) would report, more unbalanced scores in measures of adaptation demonstrated greater stress in overall family functioning. Gallimore et al. (1993) noted that adaptation (accommodation) is not necessarily defined by such variables as social class, income, job status, number of parents in the home, or parental educational levels, although these ecological resources do influence the accommodating options that are available to some families. Rather, they view accommodation from an ecocultural perspective, specifically examining how families organize their daily routines to shape the activities and development of the children within them. In creating a daily routine that maximizes child potential and reduces stress, parents develop and refine strong, effective coping strategies.

Literature supports the hypothesis that families that cope well are more able to adapt to the needs of the family unit. Thus, families that cope effectively with a child with a disability will display a flexibility sufficient to enable them to modify family roles and routines to meet the needs of their disabled child (Fagan & Schor, 1993).

Family Cohesion. Cohesion, or coherence, is defined as the sense of emotional bonding or "oneness" members of a family feel toward one another (Olson, Russell & Sprenkle, 1983). Like family adaptability, Olson (1991) depicts cohesion as a curvilinear relationship, with too much cohesion resulting in overidentification with the family or enmeshed families, and too little cohesion leading to members of the family feeling isolated, or disengaged, from one another. Normally, healthy families demonstrate a balanced cohesion between the two dysfunctional extremes (see also Russell, 1979). However, if the culture or value system of the family supports behaviour at either of the extremes, "the family will function well as long as the family members accept these expectations" (Olson, 1991, p. 12).

The Beavers Family Assessment Model (Beavers et al., 1986) utilizes the terms centrifugal, centripetal and mixed to describe the stylistic dimension of family functioning, or family cohesion. In this model, families that exhibit centrifugal functioning tend to isolate family members which may result in children who manifest behaviour problems; families that exhibit extreme centripetal functioning tend to be enmeshed, resulting in a greater proportion of children with neurotic tendencies. Beavers et al., (1986) assert that healthy families engage in a mixed stylistic pattern simultaneously creating both personal independence and attachment to the family unit, thus balancing the degree of separateness with connectedness (see also Handel, 1967). McCubbin and McCubbin (1993) note other important features of family cohesion such as trust, appreciation, mutual support, and respect for the rights of each family member.

Krauss (1993) remarked that, similar to family adaptation, mothers of children with disabilities may perceive family cohesion differently (more positively) than fathers, and that families that rank lower in measures of cohesion tend to exhibit greater overall stress. Martin and Cole (1993) studied the relationship of cohesion to the parent/child dyads that exist within the family and found that fathers involved in a marriage characterized by strong bonds of cohesion also demonstrated a cohesive father-child relationship. Conversely, husbands who were disengaged from their wives were more likely to be disengaged from their children as well. Similarly, fathers who reported strong negative reactions to the diagnosis of disability in a child often abdicated responsibility for the care of the child to the mother (Meyer, 1986). Mother-child relationships, however, were less closely related to cohesion, though high cohesion was linked to lower distress and higher marital satisfaction in mothers (Henggeler et al., 1990).

In studies of families containing children with disabilities, measures of stress are generally lower in families demonstrating high cohesion (Dyson, 1993; Friedrich et al., 1985). Thus, research supports the hypothesis that families that cope successfully exhibit a healthy cohesion, effectively balancing respect for the rights of each individual with a sense of "we're in this together."

Family Hardiness. Hardiness is defined as the internal strength or "durability" of the family characterized by factors such as the family's ability to accept responsibility and control consequences, a healthy perception of change, and active rather than passive approaches to stressful situations (Beavers et al., 1986; McCubbin & McCubbin, 1993).

Therefore, families that achieve high measures of hardiness usually have strong interfamilial relationships, view stressful events as a challenge rather than debilitating, and employ a greater variety of coping strategies to solve problems

(Failla & Jones, 1991). Mahoney et al. (1992) reported that "the support family members provide each other . . . appears to be the major contribution to family adjustment" (p. 401).

Family Creativity. Creativity refers to the ability of the family to produce both a sufficient number and variety of solutions to difficulties encountered (Russell, 1979; Beavers et al. 1986). Some research indicates that family problem solving skills are utilized differently by mothers and fathers. Strong problem solving skills have been found to be related to positive adjustment in fathers (Krauss, 1993) and lower measures of stress in mothers (Miller et al., 1992) of children with disabilities. It is hypothesized that the ability to generate effective solutions to such potential difficulties as educational placement and child care issues leads to feelings of competency and satisfaction, especially among fathers (Frey, Fewell, & Vadasy, 1989). Mothers, on the other hand, achieve more satisfaction from generating solutions related to child functioning variables such as toiletting, dressing and eating (Frey, Fewell, & Vadasy, 1989).

A strong correlation between cohesion and problem solving strategies was found by Trute and Hauch (1988), who reported that in families with strong coping skills, the family members could "discuss and debate alternate choices in family activities while maintaining a high commitment" to one another (p. 191). As well, Kirkham et al. (1986) have reported that family members can improve their problem solving abilities through engaging in role-playing activities.

Family Roles and Responsibilities. Family roles refer to the division or assignment of responsibilities within the family unit. In families that function smoothly, the roles of the various family members are often redefined to incorporate the caretaking needs of the members with disabilities (Fewell, 1986a; Rousey et al., 1992), yet not allowing the needs of that one member to become the controlling factor around which the family is structured (Beavers et al., 1986). Thus, roles may be defined more rigidly (Martin & Cole, 1993) and unusual family structures may emerge as the norm within these families (Beavers et al., 1986). Family members may also be required to take on duties normally performed by teachers, physiotherapists, language pathologists, and aides (Fewell, 1986a; Moeller, 1986).

Some studies note that fathers are less likely to participate in caretaking responsibilities when their children (especially male children) are disabled (Bristol, Gallagher, & Schopler, 1988; Dunst et al., 1986b; Willoughby & Glidden, 1995). However, the participation of fathers in child care, when it does occur, enhances marital satisfaction for both partners (Barakat & Linney, 1992; Willoughby & Glidden, 1995). Other studies report stress created by the roles siblings are required to play in the family unit (Morgan-Redshaw, Wilgosh, & Bibby, 1991). Fewell (1986a) noted that the oldest siblings, particularly girls, are often given additional responsibility for siblings with disabilities. Yet in the midst of these differences, families that cope successfully maintain a healthy balance of power between the various members of the family (Beavers et al., 1986; Gallimore et al., 1993), allow each family member a voice in decision-making concerning the functions they fulfil, and value the roles they perform to benefit the family as a unit

(Dyson, 1991).

Family routines refer to the organizational structure or pattern that families create to manage the necessary activities of daily life. Routines give stability and continuity not only to the daily schedule but also to the roles that family members employ in order to carry out the routines (McCubbin et al., 1993). The presence of a child with a disability may result in the disruption of the family's normal routine structure as well as the family's attempts to accommodate routines to meet the needs of the child (Gallimore et al., 1993, Hamlett et al., 1992). Many families containing a child with a disability have found set routines to be both helpful and highly valued (Dyson, 1993). Structured routines also serve as a vehicle for teaching important concepts through modelling, joint participation, and repetition (Gallimore et al., 1989). Studies have concluded that families that attempt to preserve their normal routines even in the midst of distress are more likely to have positive family functioning (McCubbin et al., 1993). However, similar to "normal" families, the bulk of homecare responsibilities in families containing children with disabilities often is carried out by mothers (Barnett & Boyce, 1995).

Family Composition. Composition refers to the general make-up of the family, the position each member holds within the family, and the relationships between them. Again, research is inconclusive. Some studies contend that two-parent families, especially those containing fewer children, are generally more adept at coping with a child with a disability (Trute & Hauch, 1988). Beavers et al. (1986) concluded that though families with two adults were stronger in coping skills, the adults need not necessarily be a married couple. Family units consisting of grandparents, foster or step-parents, or even close relatives or other relationships were equally facile at coping, as long as there was support and a sense of interdependence between the adults (see also Fewell, 1986a, and Fagan & Schor, 1993). Though in many studies single mothers were found to be as adept at coping as married mothers, the strategies used were often different (Flynt & Wood, 1989). Married mothers tended to rely more on intra- and interfamilial supports while single mothers were more likely to make greater use of social supports (Trivette & Dunst, 1992). Single mothers generally employed fewer coping strategies, perhaps due to their more limited family structures (Flynt & Wood, 1989).

Other family variables. The social economic status (SES) of the family was cited in a number of studies, with a lack of consensus. Some studies indicated that SES had little or no relationship to family adjustment (Dote-Kwan & Hughes, 1994; Flynt & Wood, 1992; Gallimore et al., 1993; Trute & Hauch, 1988), though others report that families with higher income have more choices available to assist them to cope (Friedrich et al., 1985; Trute & Hauch, 1988; Willoughby & Glidden, 1992) and demonstrate higher paternal (Willoughby & Glidden, 1995) and maternal (Barakat & Linney, 1992) satisfaction. Poorer families may utilize primarily familial supports (Wikler, 1986), while families with higher socioeconomic status seem to have more varied support networks (Barakat & Linney, 1992). In some families, the financial needs created by the presence of a disabled child in the home have required both parents to be employed; nevertheless, several studies found no relationship between maternal employment and measures of overall satisfaction (Trivette & Dunst, 1992; Willoughby & Glidden, 1995).

Another family variable that emerged in several of the studies was family moral/religious orientation. Families who value both their children with disabilities and their role as a caretaker of a "special" child generally tend to be healthier and more adept at coping than other families (Abbott & Meredith, 1986; Beavers et al., 1986). Often these values stem from reframing the family's beliefs about disability (McCubbin et al., 1993) or from a religious understanding of the child's life and disability (Erin, Rudin, & Njoroge, 1991; Fewell, 1986b; Hancock et al., 1990; Mahoney et al., 1992; Weisner, Beizer & Stolze, 1991). As well, some parents may deal with guilt through a religious context, modifying or deepening their own personal beliefs (Erin et al., 1991), while others look to religious themes to answer many of the existential questions surrounding the impact of their child's disability on their lives (Fewell, 1986b).

Although some families found in their religious communities support for such needs as childcare and meeting financial burdens, other families reported that the religious communities themselves were unprepared to deal with the needs of a child with a disability (Erin et al., 1991). It might be argued that some of the benefit of contact with a religious community is that it acts as an additional support network (Fewell, 1986b; Wikler, 1986). However, the appraisal impact of specific faith orientations cannot be overlooked (Abbott & Meredith, 1986).

In a study of 80 mothers of children with Down syndrome, Fewell (1986b) reported that while mothers were split over the benefits accrued from belonging to religious organizations, 66% reported obtaining comfort and support from personal spiritual beliefs and practices. At the same time, parents often reported frustration and anger when family members or friends over-spiritualized the experience of parenting a child with a disability. Weisner et al. (1991) concluded that although religious parents were likely to emphasize family values and child nurturing, there were no differences in measures of emotional adjustment between religious and nonreligious families.

Finally, McCubbin and McCubbin (1993) mention time as an important family variable that is often overlooked in assessing the needs of families with dependent children. Time can be either a stressor due to the seeming inability to fulfil all of the caretaking requirements of a child with a disability, especially for mothers (Bailey et al., 1992; Barnett & Boyce, 1995; Fewell, 1986a), or a coping strategy for parents and/or other family members to gain occasional relief from the responsibilities of childcare (Todis & Singer, 1991). Parents often report less than adequate time spent with their spouses and nondisabled children, and almost no time for self-nurturance (Bailey, Blasco, & Simeonsson, 1992; Fewell, 1986a) Trivette and Dunst (1992) report that "increased time demands were reported by respondents with lower incomes, lower role satisfaction, less formal support, and children with lower IQs" (p. 377).

Parent Variables

In addition to variables that involve the entire family, other variables emerge from the study of literature that relate more specifically to the parent dyad or to individual parent dimensions of coping. The following are summarized below: (1) quality of marital relationship, (2) maternal locus of control, (3) parental appraisal, (4) concerns about the future, and (5) other parental variables.

Quality of Marital Relationship. The effects of child disability on the marriage relationship of the parents can be either positive or negative (Martin & Cole, 1993). However, in studies of two-parent families containing a child with a disability the quality of the marriage has emerged as one of the strongest predictors of family health (Dyson, 1993; Fewell, 1986a; Friedrich et al., 1985; Simons et al., 1993; Saddler, Hillman, & Benjamins, 1993; Trute & Hauch, 1988; Wikler, 1986). This may be due to the fact that in stronger marriages support from a spouse is more evident (Abbott & Meredith, 1986).

Although in some research the divorce rate in families containing children with disabilities is no different than that of other families, parents who do divorce often report lower marital satisfaction prior to the presence of the child with disabilities (Crnic et al., 1983; Meyer, 1986; Wikler, 1986). Some parents also report that the presence of a child with a disability has strengthened their marriages (Lesar et al., 1995; Meyer, 1986). Parents who do cope effectively seem to engage in a parental coalition that enables them to share the parental responsibilities, support one another over time, acquire a realistic perception of their child, and value the contributions each parent makes to facilitate family functioning (Abbott &

Meredith, 1986; Beavers et al., 1986; Friedrich et al., 1985; Hamlett et al., 1992; McCubbin & Mc Cubbin, 1993).

Maternal locus of control. Locus of control is defined as the extent to which a person believes that events in his/her life are governed by factors external or internal to his or her power. Mothers of children with disabilities often face demands on their time and energy that are excessive (Dunst et al., 1987; Fewell, 1986a; Martin & Cole, 1993; Moeller, 1986). Because of these demands many studies indicate that these mothers have higher rates of pessimism, stress, and depression (Krauss, 1993; Rousey et al., 1992; Wikler, 1986). Studies of locus of control in mothers report that though some studies show no correlation between measures of locus of control and stress in mothers of children with disabilities (Krauss, 1993), mothers who believe they can make things happen and have control over outcomes are more likely to experience adaptive family functioning and access social supports more effectively (Friedrich et al., 1985; Rimmerman, 1991).

Parental appraisal. Studies of coping in families containing children with disabilities have indicated that the role of fathers has long been misunderstood and even perhaps overlooked (Meyer, 1986). Though some studies indicate that measures of stress are similar for both mothers and fathers (Rousey et al., 1992), certain aspects of the father's behaviour specifically influence family outcome. (See Meyer, 1986, for an extended discussion of fathers of children with disabilities.) Fathers who believe they are competent to meet the needs of all their children have lower measures of stress than fathers who question their parental competencies

(Krauss, 1993). Research has also shown that fathers often experience more difficulty in relating interpersonally to their children who are disabled (Beckman, 1991). Because stress in fathers is often related to child temperament (Krauss, 1993), the father's perception of the child and family situation has been shown to predict both the mother's perceptions and the child's social competence at a later date (Frey, Fewell, & Vadasy, 1989; Meyer, 1986). Similarly, Miller et al. (1992) report that positive appraisal is associated with maternal adjustment. Parents who cope well also view their situation as better than others, have confidence in their coping resources, and have higher perceptions of personal control than parents who exhibit strain (Frey, Greenberg, & Fewell, 1988; Miller et al., 1992).

Concerns about the future. There are indications that parents of children with disabilities experience increased stress and pessimism about their children's futures over time (Abbott & Meredith, 1986; Dyson, 1993; Fewell, 1986a; Friedrich et al., 1985). This could be due to the escalation of caretaking demands associated with an older child, the diminution of energy levels of the parents, increased financial concerns, the inability to locate adequate long-term resources, or the more obvious discrepancies between the child who is disabled and younger siblings or normal age peers (Beavers et al., 1986; Moeller, 1986). As well, parents may experience increased stress as the child moves through various transition phases, such as entering preschool, entering puberty, or leaving home (Friedrich et al., 1985). Concerns about the future appear to be chronic requiring parents to deal with them as along as they have responsibility for the child (Todis &

Singer, 1991). Because of these concerns many parents use such coping strategies as learning to live "one day at a time," realizing that when tomorrow comes they will have the strength to continue to manage their lives and their families (Abbott & Meredith, 1986; Roberts, 1986). Yet some parents report that future concerns are an ever-present reality in their lives (Moeller, 1986).

Other Parental Variables. McCubbin & McCubbin (1993) list six varieties of parental resources that influence coping: general intelligence of the parent(s), knowledge gathered through education and experience, personality or temperament, physical and emotional wellbeing, locus of control, and self-esteem (p. 46). Parental education level may have mixed effect. While parents with higher levels of education generally report greater levels of negative appraisals initially, their children demonstrate more positive outcomes over time (Wikler, 1986). Parent age has also been indicated as a coping variable, with older parents reporting less overall personal stress in some studies (Flynt & Wood, 1989). Finally, participation in support groups containing other parents of children with similar disabilities has been cited in several studies as leading to more positive family functioning (Abbott & Meredith, 1986).

Child Variables

Literature suggests a number of child factors that affect the ability of families to cope. The following will be summarized below: (1) degree of disability, (2) age of child, (3) communication competence of child, and (4) other child variables.

Degree of disability. Research is inconclusive regarding the effect of severity of disability on family coping. Several researchers have found no relationship between degree of child disability and outcome measures such as maternal adaptation and the ability of the family to cope successfully (Barakat & Linney, 1992; Krauss, 1993; Mahoney et al., 1992; Trute & Hauch, 1988). However, these studies inferred that degree of disability may influence the type of coping strategies utilized by the family and that, though aggregate scores obtained in these studies fell within normal ranges, families who scored highest on measures of distress were more likely to contain children with more severe disabilities (Mahoney et al., 1992).

Other studies have shown a clear relationship between severity of child disability and perception of stress (Donovan, 1988; Friedrich et al., 1985) as well as the ability of the parents to cope effectively (Cummings, 1976; Dunst et al., 1986a; Frey, Greenberg et al., 1988; Martin & Cole, 1993). Some of the discrepancies in these studies may be due to variations in the definition of severity, which might be interpreted as functional limitations associated with the disability, physiological impact, or perceived family hardship associated with the disability (Ireys et al., 1994).

It has also been suggested that other characteristics of the disability, rather than severity alone, might be influencing these results. Such features as type and visibility of disability (Fewell, 1986a; Wikler, 1986), presence of behavioural problems (Friedrich et al., 1985; Willoughby & Glidden, 1995), pervasiveness of the disability (Donovan, 1988), child intellectual level (Barakat & Linney, 1992), unpredictability of symptoms (Ireys et al., 1994), and presence of multiple disabilities including problems with speech and hearing (Ireys et al., 1994) are also associated with variability in outcome measures.

In a study of mothers of hearing impaired children, Henggeler et al. (1990) noted an inverse relationship between mothers' marital satisfaction and degree of hearing loss. Conversely, Rousey et al. (1992) noted that mothers whose children ranked higher on a scale of severity reported more satisfactory marriages, due perhaps either to their satisfaction with their own roles as caretakers or with the increased assistance provided by their husbands. However, they also noted that marital satisfaction for fathers included in the study was inversely related to disability severity, perhaps due to the same expectation of extended caretaking responsibilities. Rousey et al. (1992) similarly reported an inverse relationship between child impairment and measures of marital adjustment for fathers, though Meyer (1986) points out that other variables, such as the demands of long-term financial responsibility, may compound fathers' responses.

Other researchers contend that it is not severity of disability that determines parental adjustment, but the necessity for parents to have a realistic understanding of the child's disability and clear expectations of the child's functional capacity (Beavers et al., 1986; Fewell, 1986a). In fact, parents who focus on the positive contributions and characteristics of their children generally are more positive toward them (Abbott & Meredith, 1986; Kirkham et al., 1986). Finally, ambiguity of diagnosis creates increased stress and isolation for families (Beavers et al., 1986; Miller et al., 1992; Roberts, 1986).

Age of child. While some studies link age of child to increased family stress (Wikler, 1986), others have indicated that the age of the child has no effect on family functioning (Bailey et al., 1992; Flynt & Wood, 1989; Trivette & Dunst, 1992; Trute & Hauch, 1988). Although Trivette and Dunst (1992) contend that their results may be predicated on the small age sample of the children studied, the research by Flynt and Wood (1989) and Bailey et al. (1992) examined coping of mothers of children in a variety of age groups with similar results. Beavers et al. (1986) refer to difficulties many parents of children with disabilities experience during normal transition phases, such as beginning or leaving school, due to the educational and vocational differences between these children and their "normal" peers (see also Morgan-Redshaw et al. [1990] for a study of mothers of adolescent hearing impaired children).

Communication competence of the child. In a study which examined 48 children with severe disabilities between the ages of 8 months and 12 years, Frey, Fewell, & Vadasy (1989) report that the communicative competence of the child predicted parent adjustment scores after two years. This is especially true when children are perceived as unaffectionate or unresponsive to parental overtures (Donovan, 1988; Wikler, 1986). The issue of child communication was especially apparent in literature regarding children with sensory impairments. Dote-Kwan and Hughes (1994) noted that the pragmatic ability of children with visual impairment related to the emotional and verbal responsiveness of their mothers. Morgan-Redshaw et al. (1990) indicated that though mothers of children with hearing impairment cite communication as vital to family functioning, parents are generally able to choose between the variety of approaches available within the deaf population and communicate successfully with their children.

Other child variables. A number of studies revealed similar findings that the gender of a child with a disability was a significant predictor of family function and adaptation, with parents of female children reporting better overall adjustment than parents of male children (Frey, Fewell, & Vadasy, 1989; Henggeler et al., 1990; Krauss, 1993; Meyer, 1986; Wikler, 1986). It has been hypothesized that stress levels are elevated in fathers particularly because fathers have higher expectations for sons than for daughters and fathers tend to relate to their sons through joint recreation (Frey, Greenberg, & Fewell, 1989).

Child temperament was cited in several studies. Krauss (1993) reported that fathers indicated higher levels of stress related to their child's negative temperament. Rousey et al. (1992) found that measures of pessimism in both mothers and fathers were related to child characteristics. However, Trute and Hauch (1988) found no relationship between child temperament and overall measures of family adaptation.

External Variables

Several components of stress and coping are mentioned in the literature that fall outside the scope of family, parental or child considerations. Three of these will be summarized below: (1) stigmatizing social attitudes, (2) social network supports, and (3) collaborating with professionals.

Stigmatizing social attitudes. In a study of coping in families with children who are disabled, Beavers et al. (1986) remark "a key issue for these families is their being tagged as different which results in feelings that are often blocked from expression within and outside the family" (p. 377). Parents may be perplexed over the ambiguities of the image the public holds about persons with disabilities. Especially disturbing to parents are strangers who make uninformed or crude comments about the child or who stare tactlessly at the child or family. Similarly, Hancock et al. (1990) describe the reactions of mothers of children with severe visual impairment, encompassing both their feelings of despair due to discrimination against their children and their hope that with the current move toward increased integration, "kids won't think twice about (others) being visually impaired or retarded or whatever, and just see them as kids" (p. 413).

The fact that stigmatizing social attitudes do not seem to change over time has been found to be a significant cause of stress in families of children with disabilities. (See Lesar et al., 1995, for a study of social attitudes and children with HIV infection.) Baxter and Cummins (1992) studied the degree to which three ways of coping reduced this stress for parents and family members. Remaining silent in the face of inconsiderate remarks or behaviour, controlled affect, was related to high levels of stress in family members. Similarly, moving away from the unpleasant situation, disassociation, was also related to elevated measures of stress. However, parents or family members who used verbal interaction to supply information about the child's disability to strangers reported reduced levels of stress associated with the negative event. Family members may also respond by comparing their situation more favourably to that of others (Beavers et al., 1986).

Social network support. Research clearly favours the assumption that social support is constructive in mediating the effects of personal and family stress (Barakat & Linney, 1992; Beavers et al., 1986; Hamlett et al., 1992; McCubbin & McCubbin, 1993; Trivette & Dunst, 1992). In fact, the influence of social support has been considered analogous to the beneficial effects of a strong marital relationship on stress reduction within the family (Simons, Lorenz, Wu & Conger, 1993). In families containing children with disabilities, social support has been found to have positive effects on personal and family wellbeing, as well as on parenting styles, parental attitudes and expectations, and child behaviour and development (Trivette & Dunst, 1992). Fewell (1986a) notes that close friends are the second most likely source of social support behind family members. As well, communication with other parents of children with disabilities enables many parents to embrace their initial and ongoing feelings and concerns as normal, and obtain nonjudgemental acceptance and nurturance (Roberts, 1986; Stagg & Catron, 1986; Todis & Singer, 1991). However, social support may be difficult to find (Donovan, 1988; Hamlett et al., 1992).

It is possible that mothers and fathers perceive social supports differently

(Frey, Greenberg, & Vadasy, 1988; Krauss, 1993). Research shows that the most pressing needs for mothers are assistance in obtaining information about their children's disabilities and techniques for engaging helpful social service support (Donovan, 1988; Hamlett et al., 1992; Mahoney et al., 1992; Roberts, 1986). Conversely, mothers' needs for assistance with personal or family affairs were considerably lower. In studies of mothers of preschool children with disabilities, research suggests that mothers require support more for themselves than for their children. Therefore, maternal and family satisfaction with support (or perception of adequacy of support), rather than amount of support, have been attributed to positive family functioning (Barakat & Linney 1992; Frey et al., 1989; Hamlett et al., 1992; Mahoney et al., 1992; Rimmerman, 1991). As well, families differ in the types of social support they seek, and both these types and amounts may change over time (Dunst, Trivette, & Cross, 1986b; Nixon, 1994; Stagg & Catron, 1986).

Collaborating with professionals. Parents of children with disabilities have reported difficulties interacting with professionals, even those who are specifically trained to work in the field of disabilities (Beavers et al., 1986; Hancock et al., 1990; Roberts, 1986). Meyer (1986) suggests that professionals may over-emphasize stress in initial adjustment, while minimizing the stresses during adolescence and early adulthood. Roos (cited in Meyer, 1986) intimated that physicians may approach some persons with disabilities with a sense of "professional hopelessness" due, in part, to their inability to offer either effective treatment or a promising prognosis (p. 45). As well, many parents report frustration over insensitivity on the part of professionals during initial diagnosis of disability when clearly-presented information regarding the diagnosis and prognosis is especially needed (Roberts, 1986). Professionals may also delay diagnosis or dismiss a parent's concerns about a child.

Helpful professionals, on the other hand, neither belittle nor reject parents' concerns (Moeller, 1986), but show respect for both the child and the parents (Roberts, 1986). They also assist parents by providing helpful information, skills acquisition, emotional support, and referrals to appropriate support agencies (Roberts, 1986). They can also assist parents in their efforts to more clearly set priorities and gain perspective in their lives (Moeller, 1986). However, these helpful benefits can be obstructed by professionals who expect parents to assume time and energy-consuming responsibilities for their children.

When a child enters school, some parents have reported that the tendency of professionals to emphasize the child's deficits and weaknesses has contributed to frustration and discouragement. These practices may force parents to assume positions of advocacy for their children, often taking stances in direct opposition to the professionals. However, parents that cope effectively develop effective strategies for working collaboratively with professionals.

The main finding from the literature regarding coping in families containing a child with a disability is that the number of variables involved in successful coping is extensive and that these variables affect families in a wide variety of ways.

However, several conclusions can be drawn regarding families who cope effectively. First, families that cope effectively are able to adapt successfully to the changes in roles and routines that are required to meet the unique caretaking needs of a child with a disability. Second, these families also have developed a cohesive, supportive family system.

Third, families that cope successfully promote a sense of ownership concerning both difficulties and outcomes, believe in themselves as capable of meeting family needs, and are able to engage in creative problem-solving to mediate stress effectively. Fourth, strong families display acceptance of their children who are disabled, realistic expectations of the child's abilities, and commitment to creating an environment that facilitates the growth and development of all family members. Finally, families who cope successfully are able to access inter- and intrafamilial sources, as well as external resources, to facilitate child and family management and mediate stress.

Transformational Outcomes

In a recent issue of Newsweek, the family of Ronald Reagan spoke of their experiences with the former U. S. President's recently disclosed struggle with Alzheimer's disease. Describing their new found family unity as a result of this crisis, Mrs. Reagan commented, "I think any illness brings a family closer together. It brings things into focus and should shuffle your priorities" (Clift, 1995, p. 32). Studies of survivors of extreme crisis events such as rape, torture, sudden death of a family member, or internment in concentration camps also demonstrate that for some individuals, the crisis experience ultimately results in personal growth and positive change (Aldwin, 1994; Davis, 1992; Janoff-Bulman, 1992; Moos & Schaeffer, 1986). The individual attests to having been transformed in some way through the process of coping with a crisis event.

Aldwin (1994) cites four ways in which a stressful situation can foster positive outcomes: (1) inoculation against future stresses, (2) increase in mastery (including positive self-esteem and internalized locus of control), (3) change in values and perspectives, and (4) strengthening bonds of social support. She remarks, "rather than simply a homeostatic function, the more important role of coping may be transformation. . . . Clearly, we need more information on how individuals can transform themselves through the process of coping with stress" (p. 270).

One reason for the lack of documentation of transformational outcomes in the literature on stress and coping might well be the emphasis placed on stress "management." If outcomes are measured in terms of reducing the negative physical or emotional effects of a stressor alone, positive outcomes may well be overlooked (Aldwin, 1994). In other words, it may be true that we can only find what we are actively looking for. Only when research questions and measurement techniques are adapted to include positive outcomes above and beyond reduction in stress will the transformative aspects of stress be documented.

However, this is not to deny the many ways in which stress is acknowledged to produce positive outcomes in daily life. "No pain, no gain" is true whether one is preparing for a gruelling athletic event or a comprehensive exam. Diet programs encourage the overweight to deny themselves (i.e., undergo stress) today in order to acquire a healthier self tomorrow. Even counsellors inform patients that the journey to healing and wholeness may involve intense pain at times. Furthermore, the goal is not to return to a former illness prone state, but to progress to a new level of self-understanding and mental health.

Aldwin (1994) points out that positively resolving crisis events in a way that facilitates growth beyond the initial state is at the heart of a number of prominent developmental theories, such as those espoused by Freud, Erikson, and Jung. As well, many religions encourage spiritual growth through implementation of self denial processes.

Proponents of systems and chaos theories contend that the linear theory "**a causes b**" cannot adequately describe all events in the real world (Janoff-Bulman, 1992; Kosko, 1993). In fact, in many instances the truth might be more accurately stated that a situation or event might be able to precipitate, even simultaneously, both negative and positive outcomes. That is, a single event may lead to increased stress in one domain and reduced stress in another. Alternatively, it might also be possible that initial changes occur within a system that do not alter the overall functioning of the system, something Watzalawick, Weakland, and Fisch (1974) refer to as "first order change" (cited in Janoff-Bulman, 1992, p. 43). Only after a period of time may these minor adjustments surface as transformative changes.

Aldwin and Stokols (1988, cited in Aldwin, 1994) suggested that certain characteristics of a stress event may predispose one to expect a transformative outcome. Stressful events that occur suddenly or at inconvenient times, involve several life domains, and are highly significant to the person, are hypothesized to result in change (p. 268; see also Janoff-Bulman, 1992, and Meichenbaum & Fitzpatrick, 1993, for similar findings). Thus, the diagnosis of disability in a child that comes as a sudden shock, involves changes in home, vocational life, and relationships with family and professionals, and challenges basic life assumptions, may well set the stage for positive or negative personal transformations to occur.

Palus (1993) defines a transformative experience as "a life event and its outcome, such that the event is given a central role within a self-narrative in causing, catalyzing, or symbolizing substantial, lasting psychological change" (p. 40). He contends that transformative experiences, especially those experiences that involve changes in self-identity, are the precipitators of growth during adulthood. Although transformations may occur as a result of any number or variety of experiences, they generally involve two phases: initial disequilibrium and reorganization (Palus, 1993, p. 43). In other words, the characteristic way of "doing things" is interrupted and a new, and hopefully superior, way of acting is substituted. Janoff-Bulman (1992) argues that it usually takes an event of traumatic proportions to serve as a catalyst for transformative change. Furthermore, since transformative experiences are largely a result of the interpretation, or appraisal, of the event rather than the event itself, transformations can occur simultaneously with the event or at some time, even a long time, afterward.

In a study of positive transformational experiences of adult men in six age categories, Palus (1993) found that while stressful events tend to produce negative results initially, the positive outcomes were "usually slower to be realized, enduring, and of a higher order (e.g., a change in values, or the ability to form satisfying relationships)" (p. 51). Furthermore, even experiences ultimately labelled negative in outcome contained some positive elements, usually involving relationship formations. Thus, transformational outcomes may not be evident in research that examines only short-term responses to stressful events. Longitudinal or life-range reflections may be needed to detect positive transformations.

While parents of children with disabilities have acknowledged being positively transformed through the experience of parenting a child with a disability, these experiences have not received much documentation in the professional literature. For example, after a fairly lengthy negative description of the plight of 25 mothers of children with severe chronic illnesses, Ambert (1992) almost reluctantly acknowledges in the final paragraph of her study that these mothers in fact "stressed the positive aspects of caring for their children" (p. 189). Some researchers attribute these acknowledgments of positive outcomes to denial or an unrealistic optimism (Aldwin, 1994; Janoff-Bulman, 1992). However, Abbott and Meredith (1986), in a study of 36 parents of children with mental retardation, noted that 88% of the parents reported positive outcomes, such as stronger families, increased patience and compassion, and greater appreciation for the simple aspects of life. Meyer (1986) also notes that fathers of children with disabilities may reframe their original appraisals to emphasize positive outcomes, such as their ability to reach out to others in need.

Janoff-Bulman (1992) refers to these changes as cognitive coping strategies which enable those who have encountered traumatic experiences to be able to integrate the event into their world-views without shattering their basic assumptions about life (e.g., that the world is benevolent, life is meaningful, and the self is worthy). She asserts that cognitive coping may be accomplished in any of three ways. First, the person may engage in positive comparisons of his or her situation with that of others or with imagined "worst possible scenarios." Secondly, a person may interpret his or her situation in a way that emphasizes self-blame rather than the fault or evil existing in the external world. Finally, a person may search for positive meaning to self or others through the experience of the trauma. Thus, to Janoff-Bulman transformations are a creative process, necessary for the resolution of crisis events and the preservation of mental health.

An even stickier problem for researchers exploring transformational outcomes is the question of how personal choice or free will impacts the transformational process. The influence of personal choice or, as Aldwin (1994) phrases it, "mindful coping" has generated considerable controversy. Clearly, one emphasis that has shaped psychology during much of the twentieth century has been based on the premise that one's development is determined by the interactions between one's genetic make-up and environmental circumstances. However, works such as Frankl's (1984) account of life in concentration camps assert that the key to survival in stressful situations is personal choice. "Everything can be taken from a man but one thing: the last of the human freedoms--to choose one's attitude in any given set of circumstances, to choose one's way. . . . in the final analysis it becomes clear that the sort of person the prisoner became was the result of an inner decision, and not the result of camp influences alone" (Frankl, 1984, pp. 86-87).

Out of his experiences, Frankl developed a theory of psychotherapy, logotherapy, which includes the principle of "tragic optimism." The central tenet of tragic optimism is that in the midst of suffering an individual can discover meaning or purpose that not only enables him or her to endure the suffering, but can bring about positive and lasting personal change. Aldwin (1994) is careful to assert that the stress event in and of itself does not produce the meaning or the change, rather it provides the opportunity, or sets in motion the process, for mindful coping to occur (p. 279). Furthermore, she argues, because stress, by definition, is something that an individual cannot contend with through usual means of coping, it may actually force the individual to choose a different strategy for resolving the crisis. Thus, stress, through positive coping, may lead to transformational outcomes.

In summary, recent research suggests that when events of significant magnitude occur in one's life, transformational outcomes may be the rule rather than the exception. Thus, research that examines how people manage life following the experience of an atypical stressful event might also attempt to explore and document beneficial transformational outcomes. As Aldwin (1994) asserts, they may be the key to personal health.

CHAPTER 3

Methods and Procedures

The process of managing life with a child who is disabled can be complex. Research methodologies used to measure this phenomenon need first to enable depth and richness of meaning to emerge at the personal level, and then to establish the credibility and reinforce the shape of these conclusions by testing them over a more comprehensive data sampling. For these reasons, both qualitative and quantitative research methodologies were utilized sequentially in this study. This chapter will examine the two phases of the study, beginning with the qualitative in-depth interviews from which the themes were drawn, followed by the quantitative survey which was designed to test the themes among a wider population.

Qualitative Methodology

Rationale for Choosing Qualitative Methodology

Most of the research describing coping in families containing a child with a disability is based on data from self-administered questionnaires. While this research has generated important information about how parents cope, it is not without its critics. Aldwin (1994) cites three difficulties with self-report measures of coping. First, she contends, research is inconclusive as to the overall validity of self-report studies. In other words, responses people give to survey questions may not be indicative of what they actually do in real life situations. Responses may be tempered either by what the respondent thinks he or she should be doing or would ideally like to be doing in a particular situation, or by what the respondent perceives the correct answer to be, regardless of his or her actual behaviour. Secondly, research is inconclusive regarding the uniformity of coping behaviours across problems, situations, or time. Because people may cope differently with the same behaviour in different domains (e.g., at home in contrast to at a restaurant or at work) or at different times (e.g., when a child is a toddler in contrast to when a child is a teenager), measures of general coping may be difficult to obtain. Thirdly, research is unclear regarding the extent to which variability in the stressor at the time of self-report may influence the responses made. It is possible that responses given to a questionnaire on a difficult day may be different from responses given to the same questionnaire on a more manageable day. As well, parents may feel positive about a strategy used one day and negative about its use the next.

Many self-report questionnaires are also limited by the pre-set definition of coping which they utilize. For example, the Coping Health Inventory for Parents (CHIP) which has been used as a measure of coping in a number of studies of parents of children with disabilities (Donovan, 1988; Failla & Jones, 1991; Flynt & Wood, 1989; Redington et al., 1995; see Table 1, Chapter 2), is a 45-item self-administered questionnaire in which coping is measured on three subscales: family cooperation, social support, and coping with the medical aspects of disability. However, this scale may overlook other important aspects of personal or family coping. Similarly, the Questionnaire on Resources and Stress (QRS), also widely used with families containing children with disabilities (Donovan, 1988; Dyson, 1991; Dyson, 1993; Flynt & Wood, 1989; Frey, Fewell, & Vadasy, 1989; Frey, Greenberg, & Fewell, 1989; Henggeler et al., 1990; Lesar et al., 1995; Rimmerman, 1991; Rousey et al., 1992; Saddler et al., 1993; Trivette & Dunst, 1992), is a 52-item self-administered questionnaire in which parents indicate whether each item is true or false for their family situation. Recently, the validity of the QRS as a measure of family stress has been challenged due to the tendency of the scale to equate mere presence of disability in a child with stress (Clayton et al., 1994; Glidden, 1993). Other studies have concentrated on such aspects of coping as family adaptation, family cohesion, and family hardiness. In many of these studies the boundaries of coping have been predetermined through the selection of instrumentation used to study the phenomenon.

However, qualitative methodology enables the researcher to approach a field of study without being restricted to predetermined construct delimitations (Patton, 1990). This approach generates greater depth, openness, and detail, and ultimately results in a more holistic assessment of a phenomenon; in other words, "it tells the whole story with all of its variations" (Borman, LeCompte, & Goetz, 1986, p. 53). Meichenbaum and Fitzpatrick (1993) report that following personally traumatic events, ". . . individuals not only offer narratives of what happened, but they also provide causal explanations (attribution) and accompanying justifications;" and, furthermore, "the content of a survivor's narrative influences the quality of adaptation to stressful events" (p. 709). Thus, some coping responses might best be explored through use of a methodology, such as interviewing, that allows the narrative to be examined. As well, Aldwin (1994) suggests that qualitative methodology should be used to explore aspects of coping that are employed unknowingly by an individual. In this study, qualitative methodology was utilized precisely for these reasons.

The use of a qualitative base/quantitative corroboration and expansion methodology is not a unique concept in the literature. In his study of the role of self-understanding in resilient individuals, Beardslee (1989) utilized an interview methodology that moved from an in-depth study of a small number of resilient individuals to a quantitative analysis of a larger and more diverse subject group. Beardslee comments, "This work represents an evolution in both conceptual and experimental terms. . . . It is based on an inductive approach that builds from individual life experiences toward a more general concept . . ." (p. 267). A similar methodology was used in a study of stress experienced by parents of adolescents with severe disability (Baine, McDonald, Wilgosh, & Mellon, 1993), and adjustment of students from Hong Kong to a Canadian university setting (Sheh, 1994). In both of these studies, results from a qualitative interview methodology were corroborated and extended through a quantitative follow-up. A similar procedure was followed in this study.

Interview Participants

Participants for inclusion in the qualitative section of the study were selected using the criteria of purposive sampling (Patton, 1990). Parents of 14 families in which one or more children with disabilities resided and who were judged to be "good copers" were nominated by personnel from the following agencies: Alberta Association for Community Living, Gateway Association for Mentally Handicapped, Glenrose Hospital, and the Alberta Children's Hospital. These participants resided in two urban centres and outlying areas in the province of Alberta.

Of the 15 parents interviewed, 12 (80%) were married and living with their spouses. Three of the parents interviewed, (20%) were single mothers. Fourteen of the 15 parents interviewed (93%) were mothers. In one interview both the mother and the father participated. Ten of the 15 parents interviewed (67%) were employed full- or part-time at the time of interview. Two other parents were extensively involved in volunteer work outside the home. Three of the parents described themselves as full-time housekeepers.

The total number of children with disabilities contained within these 14 families was 17. Eight of the children (47%) were males and nine (53%) were females. Disability conditions included profound deafness (two children), Down syndrome (three children), autism (three children), severe multiple disabilities (four children), rare genetic or other conditions (three children), undiagnosed genetic disorder (one child), and developmental delay (one child). The age range of children with disabilities at the time of interview was from 3 1/2 half to 25 years of age, with a mean age of 10 years, 3 months. The total number of children in the 14 families ranged from one to six, with a mean of 2.9 children per family. One family also contained a number of foster children who were not included in these calculations. In nine of the families (64%) the child with a disability was the first-born (and in two, the only) child.

Data Collection

The procedures utilized in this thesis followed a modified three-interview series pattern of data collection (Seidman, 1991). Parents were initially contacted by phone, informed of the purpose of the study, and invited to participate. Questions were answered and some demographic data regarding the child(ren) and family were obtained. Each parent contacted agreed to participate in the study, and an initial interview time and place were arranged.

Initial interviews. Interviews of from 1 1/2 to 2 hours were audio-recorded, using a portable cassette recorder, with each parent or, in one case, the parent dyad. Nine interviews (64%) were conducted at the parent's home, and the remaining five interviews (36%) were conducted at an office or place of business of the parent's choosing. Prior to the interview, each parent signed a written consent form assuring them of anonymity and permission to withdraw from the research at any time. (See Appendix A for a copy of the consent form.)

The interviews were conducted using the interview guide approach (Patton, 1990) in which topics to be covered were specified in advance, yet allowing the interviewer options for determining both the sequence and wording of questions. According to Patton (1990), this approach allows for comprehensiveness of data collection while preserving the conversational nature of the interview. The open interview approach also allows individuals to tell their own unique stories about how an event has impacted their lives and how they and their families have reconstructed their lives as a result of the event and its consequences (Janoff-Bulman, 1992; Meichenbaum & Fitzpatrick, 1993; Seidman, 1991).

The interview began with the request: "To get started, tell me a little bit about your family." This provided both context and setting for the narrative. If the information was not included in the initial response, the interviewer asked, "When did you first discover (child's name) had a disability?" This gave the narrative a starting point and the story followed largely chronologically, covering such topics as initial diagnosis, infant and pre-school years, transition to school, and so forth. As the parent(s) described various life events, the researcher would ask, "How did you manage that situation?" or "What helped you get through that incident?" These questions were designed to explore life management strategies, Question 1 of the study.

After the basic narrative had been sketched, the researcher asked a question such as, "What personal characteristic(s) has/have been most important to you as you have parented (child's name)?" or "If you could design a parent for (child's name), what personal characteristic(s) would you give to this person?" These questions were designed to examine additional parental characteristics, Question 2, that may or may not have been covered in the narrative section of the interview.

Toward the end of the interview, the researcher asked such questions as, "How have you been changed through parenting (child's name)?" or "What has (child's name) taught you through his/her life?" These questions were designed to explore transformational outcomes, Question 3, if they were not mentioned during other portions of the interview. Additional questions were asked through the interview for purposes of extension or clarification of parent responses.

Each of the 14 interviews was transcribed by the researcher and a copy of the transcription was mailed to the participant(s) for verification, clarification and, in some instances, modification. This process of testing the data with the sources, sometimes called "member checks" (Guba & Lincoln, 1983), increases the credibility of the interview protocol, or raw data. Four of the participants also received theme analyses of their transcripts for verification.

Follow-up interviews. Twelve of the parents were contacted for follow-up interviews. Nine of the participants elected to meet with the researcher a second time for a follow-up interview. Due to time or distance constraints, three participants elected to be interviewed by phone. One participant could not be reached for a follow-up interview due to a change of residence, a possibility she alluded to during the initial interview. Follow-up meetings averaged 1 hour 45 minutes, and phone calls averaged 30 minutes.

Prior to the follow-up interview, each participant received a copy of the themes and sub-themes extracted from the original 14 interviews. The major portion of the follow-up interview was spent discussing the nine themes, which resulted in changes made to several sub-themes.

Data Analysis

All 14 interviews were recorded and transcribed prior to analysis of the data. This was done to "avoid imposing meaning from one participant's view to the next. . ." (Seidman, 1991, p. 86) and to give each narrative autonomy. Thirty minute portions from two transcripts, selected at random, were verified through audio-tape/transcript inter-rater checks (using the formula of number of agreements divided by the sum of agreements and disagreements with the result multiplied by 100). One error was found in the first transcript selected (omission of the word "up"), resulting in a transcript word accuracy of .99 for the 30 minute segment. Fourteen errors were found in the second transcript selected (five word omissions, and nine transcript inaccuracies, e.g., "he" rather than "she"), resulting in a transcript word accuracy of .99 for the 30 minute segment.

The major focus of the data analysis was on the three questions the study was designed to answer. First, each transcript was read several times to familiarize the researcher with the content. Then the entire interview was analyzed by tagging each meaning unit in the protocol. (See Appendix B for an example of the tagging procedure.) Seidman (1991) suggests that novice researchers "err on the side of inclusion" (p. 91); thus, the entire interview was tagged.

Next the tags were clustered into broader categories, which were constructed following the guidelines set forth by Guba and Lincoln (1983). Criteria for inclusion within a category consist of data that are relevant to the category, data that describe, explain, exemplify or reinforce the category, data that link sub-categories, and data that denote new aspects of a category (p. 99). Category closure is reached when data saturation occurs, meaning little novel information is generated through additional interviewing. Finally, themes and sub-themes were formed from data contained within the categories. (See table 2, Chapter 4, for list of themes and sub-themes.)

Triangulation

Guba and Lincoln (1983) recommend that "structural corroboration," or triangulation, should be employed in qualitative research to increase the credibility of the findings (p. 106). Patton (1990) specifies four types of triangulation: (1) methods triangulation, (2) triangulation of sources, (3) analyst triangulation, and (4) theory/perspective triangulation. The first three types, which were suitable for this research, have been utilized in this study.

Methods triangulation. Methods triangulation involves use of two or more methodological paradigms for collecting and analysing data. In this study, both qualitative and quantitative methodological paradigms were utilized. However, as Patton (1990) points out, the two paradigms, while possibly leading to convergent validity, may nonetheless be difficult to integrate. Furthermore, the researcher may place more weight on the findings of one methodology over the other. After utilizing a qualitative methodology in which insights are reached through collaboration with participants, researchers may feel thwarted with subsequent survey responses when access to participants is impossible. Nonetheless, when the results utilizing the two methodologies are analogous, the conclusions arising from the research are more convincing.

Triangulation of sources. Triangulation of sources involves utilizing a variety of sources to confirm the credibility of the data collected. When consistency is observed through comparing two or more data sources, the data used for analysis are more substantially validated. Eight of the participants in this study (53%) provided the researcher with material in pamphlet, article, or book chapter form, in which they described their experiences parenting a child with a disability. In every case, the written material confirmed the information shared through the interviews, and in several cases even the words used were surprisingly similar. This increases the likelihood that the interview protocol, in fact, contained an accurate description of the parenting experience from the parent's perspective.

Analyst Triangulation. Analyst triangulation involves use of a variety of evaluators to analyze the data. In this study, two interviews, chosen at random, were coded independently by two individuals, one a doctoral student who had completed a course in qualitative research methodology, and the second a professional librarian with college level teaching experience and interest in sociological research. These two evaluators were given unmarked copies of the two protocols to analyze. Following their analysis, each was presented with a copy of the theme analysis done by the researcher.

Results from the two analyses supported all nine of the major themes, though modifications were made to several sub-themes. For example, changes were made to the original religion category, dividing it into two sections: one pertaining to internalized expressions of personal faith or spirituality, such as prayer or meditation, and the other pertaining to the external aspects of organized religion, such as congregational or pastoral support. This change was made to accommodate those parents who reported that, while they found significant strength in their own personal belief system and faith practices, they found their local churches to be generally unsupportive of or unprepared to address the needs of families with persons who are disabled within the congregations.

These three methods of triangulation were used to enhance the credibility of the themes generated through the study.

Validity

Maxwell (1992), in an effort to relate the concept of validity to qualitative research without distorting the assumptions underlying qualitative research, suggested five uses of the term validity: descriptive validity, interpretative validity, theoretical validity, generalizability, and evaluative validity. Descriptive validity involves the extent to which the data represent a factual or actual account of what took place. In this study, descriptive validity refers not only to the accuracy of the transcripts, which were checked through ratings of transcriber agreement, but also the non-verbal nuances of facial expression and vocal pitch or stress used during the interview. Since message intent is often more important than actual words spoken, returning the transcripts to the participants for feedback and clarification increases descriptive validity.

Interpretive validity refers to the extent to which the meanings attributed to the words spoken reflect correctly the experiences of the participants. This assures that the analysis of the data portrays an "emic" perspective; that is, it portrays the meaning of the construct from the view of the participant. To increase interpretive validity, this study contains both "thick" descriptions and direct quotes from the participants (Maxwell, 1992, p. 289). In other words, it is well grounded in the actual language of the participants.

Theoretical validity refers to both the categories the researcher employs to classify the themes, as well as the relationships that the researcher postulates as existing between categories. In this study, four participants received the results of the thematic analysis for verification and clarification. Generalizability, or the extent to which conclusions reached in the research can be applied to the population at large (external validity), is questionable in qualitative studies in general and in interview studies as a whole. While use of the quantitative questionnaire in this study may give support to the conclusions, it cannot assure generalization to persons whose experiences in parenting may be different from those who participated in the interviews. However, the intent of the study is to describe the construct of life management from the experiences of the participants and then to offer to parents and professionals suggestions of how others have managed life, rather than to suggest that their experiences must be similar.

Finally, evaluative validity refers to inferences or interpretations drawn from that data. Because in qualitative analysis the researcher is the "instrument" (Patton, 1990, p. 472), certain procedures must be followed to avoid Type I error, in which data are judged to be insignificant when in reality they are significant, or Type II error, in which significance is attributed to data that are insignificant. One means of achieving evaluative validity, as has been discussed previously, is to return to the participants for confirmation of the analysis. A second means of assuring evaluative validity is to present the data to the reader in a way that enables the reader to draw his or her own conclusions. Thus, in qualitative research, the data are set forth using thick descriptions and direct quotations and the reader is invited to judge the validity of the inferences made. This differs from quantitative research where validity is strictly controlled *a priori* with randomness of sample and use of control groups.

Bracketing

Bracketing is the procedure qualitative researchers employ to reduce the likelihood of researcher bias affecting results. It is postulated that by identifying and isolating his or her beliefs about a topic prior to conducting a study, the researcher will be enabled to approach data collection and analysis with increased objectivity (Patton, 1990).

This researcher's personal experience with parents of children with disabilities stems from having taught children with a variety of disabilities from pre-school through high school (ages 3-21) in conjunction with two Canadian public school boards. In this role, the researcher had frequent contact with parents. Aside from being a teacher, the researcher is also a parent of three children, none of whom has a disability. Upon self-examination of beliefs corresponding to parenting a child with a disability, the researcher isolated the following five conclusions: (1) parenting a child with a disability must be at best a stressful experience; (2) persons who are professionally trained to work with children with disabilities are best equipped to make decisions regarding the educational placement of these children; (3) professionals provide a much-needed and helpful service to parents and their children; (4) parents are often evaluated by teachers and other professionals as to how compliant they are with the decisions of the system, that is, how "easy" or "difficult" they are to deal with; and (5) interaction with parents, while important, can be one of the most complex aspects of teaching children with disabilities.

Having identified these assumptions, the researcher was initially surprised by the intensity of some of the comments made by parents regarding their experiences with professionals. As well, comments related to transformational outcomes were initially overlooked. Only after the first several interviews were completed was the researcher aware that these parents, in fact, were expressing positive outcomes. As the study progressed, all of the assumptions of the researcher regarding parents of children with disabilities were challenged. Patton (1990) confirms that changes within the researcher during the course of the study, which are often inevitable, will not affect the outcome of the study if the researcher continues to monitor his or her belief modifications (p. 175).

Ethics

One of the difficulties when undertaking research is that the process may have a negative effect on the participants. In interview studies in particular, reliving difficult events may result in exposing unresolved or potentially harmful memories (Patton, 1990). To reduce this possibility, researchers must adhere to ethical practices designed to protect the participants.

Because the majority of the participants in this study have been involved in previous research studies or had previously presented their stories in oral presentation or written form, the overall probability of negative impact resulting from the interview process was judged to be small. Nevertheless, agencies who recommended persons for inclusion in the study had referral processes in place in the event of negative participant outcomes. No such outcomes were noted by the researcher.

Prior to participation in the study, all parents were requested to sign a consent form (see Appendix A), indicating their willingness to participate in audio-taped interviews, guarantying anonymity to themselves and their families, and granting them control of their interview data. They were given the right to delete, modify, or add information contained within the written transcript throughout the study and to withdraw from the study at any time. These procedures were in keeping with the research guidelines set forth by the University of Alberta.

Quantitative Methodology

Rationale for Choosing Survey Methodology

Quantitative research can be an important means of refining and further establishing the credibility of qualitative research insights by more rigorously testing them against a broader empirical base. In this study, the findings from the qualitative interviews were corroborated and extended through the use of a survey, the Life Management Survey (LMS), the purposes of which were threefold. First, the survey was employed as a means of extending the findings to a wider sample population. In other words, the survey was used to determine the extent to which the findings generated from a sample of 15 parents could be extended to a larger sample of parents. Use of a survey enabled this to be investigated with greater ease than continued use of an in-depth interview technique.

Secondly, the survey was utilized as a means of generating new information through inclusion of guided open-form response sections. Parents were invited to suggest additional strategies they use, parent characteristics important to them, and transformational outcomes they have experienced beyond those that were included in the survey. These open-form response sections generated additional data to describe the experience of parenting a child with a disability.

Finally, the survey was used to increase the credibility of the initial research findings. Use of both the survey and the review of literature to corroborate the themes drawn from the in-depth interviews has strengthened the findings and served as a counterbalance to the threat of researcher bias.

Construction of the Life Management Survey (LMS)

The Life Management Survey (See Appendix C for a copy) was composed of 59 statements parents were to rate on a five-point Likert scale. These statements were constructed from the themes generated by the qualitative analysis of interview data. Table 2 depicts the relationship between each item of the LMS and the nine themes which emerged from the qualitative study. Statements 1-31 covered the themes and sub-themes pertaining to life management strategies. Parents were asked to rate the importance of various strategies to their own parenting success along a scale using the five categories: not important, somewhat important, important, very important, and essential. For statements 32-43, parents were asked to rate parent characteristics important to them along the same 5-point Likert scale. Statements 44-59 portrayed parental changes (transformations) that parents were asked to rate on a five-point scale composed of the following categories: strongly disagree, disagree, uncertain, agree, and strongly agree.

Following each question and at the end of each of the three sections, space was provided for open-form responses, proceeded by the word "comment," or the phrases "other strategies that work for you," "other parent characteristics important

Table 2: Relationship of Items on the LMS to Qualitative Themes.

Theme 1	Statements 1 - 12
Theme 2	Statements 13 - 18
Theme 3	Statements 20 - 25, 28
Theme 4	Statements 32 - 41
Theme 5	Statements 19, 26, 27, 42
Theme 6	Statements 29 - 31, 43
Theme 7	Statements 44 - 51
Theme 8	Statements 52 - 55
Theme 9	Statements 56 - 59

to you," and "other changes you have experienced." The survey also contained a section for reporting demographic data under the headings family information, child information, and parent/guardian information.

After several drafts, the final LMS draft was pretested for comprehensibility of statements with three parents, two of whom were interview participants and a third who was not previously involved in the study. Several minor changes in wording were made to the survey.

Survey Distribution and Response

Distribution of the LMS was coordinated by personnel associated with an agency in Alberta that represents and serves persons with a variety of disabilities and their families. Two hundred copies of the survey were mailed in November, 1995, to parents of families containing children with disabilities who were judged by agency personnel to be managing life effectively. Each survey was accompanied by a cover letter (see Appendix D) which described the study and requested that surveys be returned anonymously in a stamped envelop addressed to the researcher.

Nine of the surveys were returned due to address errors and two were returned blank without explanation. Of the remaining 189 surveys in circulation, 63 were completed and returned by the December deadline. In January, 1996, a follow-up letter (see Appendix E) was mailed which resulted in the return of 17 additional surveys. In total, 80 surveys were returned and used in the analysis. (One additional survey was returned completed after the deadline had passed and was not used in the data analysis.) This resulted in a response rate of 42.3% (80/189).

CHAPTER 4

Results of the Study

The results of this study will be presented in three parts. First, the nine themes which emerged from the qualitative analysis of the 14 interviews involving 15 parents will be examined. Second, the results of the survey will be presented. Finally, the results of the cross-tabulations of the Life Management Survey will be summarized.

Qualitative Analysis of Themes

The nine themes that emerged from this study are presented in Table 3. The themes will be examined corresponding to the three questions which formed the structure of the interviews.

Question 1: What are the various strategies parents of children with a variety of disabilities use to effectively manage life?

The purpose of this question was to ascertain whether global strategies used by parents of children with disabilities to manage life could be identified across disability types and child ages. Three themes emerged from this study: (1) positive reframing of one's thoughts and attitudes about one's circumstances, or the need expressed by many parents to modify or change their feelings or judgements about either their child, their circumstances, or themselves, (2) maintaining a workable

TABLE 3. Summary of Themes from Qualitative Analysis

QUESTION 1: What are the various strategies parents of children with a variety of disabilities use to effectively manage life?

THEME 1: A positive personal reframing of one's thoughts and attitudes about one's circumstances that involves:
- (a) acceptance of the child as he/she is.
- (b) a determination to succeed.
- (c) discovery of a sense of purpose or meaning in the event.
- (d) enhancing feelings of competence and self-confidence.
- (e) development of the ability to live successfully with indeterminacy.

THEME 2: Maintain a workable balance with respect to personal roles and responsibilities (that is, "who I am" and "what I do").
- (a) Individual - establishing and nurturing physical and emotional health.
- (b) Spouse - value and nurture marriage.
- (c) Parent of child with special needs - balancing roles of parent, teacher, and advocate
- (d) Parent of other children
- (e) Employee - Employer
- (f) Educator of Society

THEME 3: Ability to meet personal, child, and family needs by locating and utilizing resources effectively.
- (a) Gathering information.
- (b) Collaborating with professionals.
- (c) Connecting with other parents or parent support groups.
- (d) Utilizing other sources of support.

QUESTION 2: Is it possible to identify personal attributes or abilities that characterize parents who manage life effectively?

THEME 4: Personal character traits.

THEME 5: Decision-making and problem-solving ability.

THEME 6: Philosophy of life.

QUESTION 3: Is it possible to extract a common theme or themes describing how parents are transformed through their parenting experiences?

THEME 7: Personal transformations - Who I am.

THEME 8: Relational transformations - How I relate to other people.

THEME 9: Perspectival transformations - How I look at life.

balance with respect to personal roles and responsibilities, and (3) acquisition of resources needed to assist the parent in the task of nurturing a child with special needs. These themes are discussed in this section.

It is important to note, at the outset, that for inclusion in this study, themes and sub-themes had to be verified by at least half (50%) of the participants. Therefore, while only a few of the participants might identify with all nine of the themes and their corresponding sub-themes, themes were included if a minimum of 50% of the participants interviewed indorsed them.

Theme 1: A positive personal reframing of one's thoughts and attitudes about one's circumstances. As was discussed earlier, the initial diagnosis of disability in a child is traumatic for the parent. Parents interviewed in this study reported feelings of isolation and aloneness from hospital staff and others, being robbed of joy, and profound devastation connected with the diagnosis of disability in their child. Of the 15 parents interviewed, 13 (87%) expressed feelings of devastation regarding the diagnosis of disability. Of the two parents who did not report feelings of devastation, one was an adoptive parent and the other expressed "relief" that a diagnosis obvious to herself and others had finally been made by the medical community. Interestingly, in eight (57%) of the families, the parents were already aware of developmental delays in their children prior to acknowledgement by their children's physicians. However, as one parent remarked, "it's devastating no matter when it comes."

Two other major difficulties surrounded the initial diagnosis of disability.

Of the 14 families represented in the study, 10 (71%) reported frustration regarding insufficient information concerning their child's disability, and 13 (93%) reported frustration concerning their child's uncertain prognosis. Other difficulties mentioned by some of the parents were lack of privacy, stressful neonatal intensive care experiences, encounters with other sick or dying children, the manner in which the initial diagnosis was shared, and having to inform the spouse or other family members about the child's disability. Clearly, for the large majority of parents interviewed, the initial diagnosis of disability in their child was a stressful, traumatic experience.

However, though many parents interviewed initially appraised their child as valued and loved, they nonetheless viewed their circumstances as difficult and their ability to parent a child with a disability as uncertain. It was only as they began to modify the way in which they perceived of or appraised their circumstances, or perhaps even constructed an entirely new way of evaluating their circumstances, that they were able to view their own lives and their corporate family lives as potentially "manageable." That is, the parents engaged in the process of reframing (reformulating) their original thoughts and attitudes about their circumstances, which now included parenting a child with special needs.

This reframing process usually included the following components: (1) acceptance of their child as he/she is, (2) a determination to be successful, (3) a discovery of a sense of purpose or meaning in the event, (4) enhanced feelings of competence and self-confidence, and (5) the development of the ability to live successfully with indeterminacy. These five components of parent reframing comprise the sub-themes of theme 1.

Sub-theme 1(a): Acceptance of the child as he/she is. While the large majority of parents had no difficulty valuing and loving their child (positive appraisal), many expressed an initial disbelief or denial of the permanency or extent of their child's disability. The mother of a child with moderate, multiple disabilities remarked, "When the doctor tells you that your child is behind and mentally handicapped, then that's not something you want to hear--so you're going to prove him wrong. So you get out there and you do whatever you have to in order to make that a reality. Eventually it comes to the point where your life goes on and you realize that it doesn't matter what you do, you're not going to change what's happened. This is who your child is." While for some parents this may result in little more than resignation; for these and other parents, acceptance of their child marked the end to the exhausting search for an elusive cure for their child's disability and freed them to concentrate on the present.

For many parents, acceptance of their child's disabling condition was a process that occurred over time. One mother recounted the bargaining process she engaged in with God as part of the process of coming to terms with her child's disability. "You know, I bargained with God. I could handle all this for the next year if he just smiled or if he learned how to walk or talk. . . . A year later he hadn't changed at all. And I remember being hit on his birthday thinking I made this deal and he hasn't changed. . . . And I looked back at that point and realized that nothing had changed, except that I'd learned to love him [for who he is]."

Several parents spoke of a distinct time when, as one aptly remarked, "reality clicked in" and they realized the need to give up the dream of a "normal" child and "get down to the business of raising the one I had." Giving up the dream and accepting a child's limitations gave a number of parents the ability to reframe their attitudes about parenting a child with special needs. As well, as they came to terms with the things about their children that could not be changed, they claimed to become more open to the possibilities of what could be changed. In fact, several parents reiterated the words of the Serenity Prayer as accurately describing how they attempt to manage aspects of their child's disability; "God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference" (attributed to R. Niebuhr).

Thus, parents reframed their initial sense of devastation associated with the diagnosis of disability into a willingness to accept their child as a child who has a disability. For several, even the term "accept" seemed shallow. They remarked that not only have they accepted, but they have even learned to embrace the changed circumstances in their lives. Having a child with special needs has helped them realize that life has both positives and negatives, mountain tops and difficult times, and they have discovered that by affirming all that life entails they are more able to remain stable, even when life throws them "curves."

A number of parents reported that as they began to reframe their attitudes toward their circumstances, and as they began to accept their children as they "are," a subtle shift began to take place in their perspective. They began to be less self-focused and more child-focused. While concerned about their children's often severe disabilities, these parents also emphasized the positive attributes of their children, such as their compassion toward others, their tenacity in the face of great odds, their positive spirits, their generosity, their warm personalities, and their ability to bring humour into often difficult family circumstances. One mother remarked, "C____ is my teacher, my mentor, my inspiration. I just see his willingness to go out into the world every day and face every challenge with joy and acceptance. He doesn't let things get him down. . . . He's taught me about unconditional love. No matter how people act toward him, he's always there with hugs and smiles."

Acceptance enabled the parents who were interviewed to see life, not just from their own point of view, but from that of their child. These parents respected their child's likes and dislikes, their goals, and their dreams. These parents also addressed the importance of celebrating their children's accomplishments, whether gaining a pound in intensive care, staying on task through a difficult problem, or achieving a goal in school. Several parents also stressed the need to create opportunities for success for their children, since they so often experienced failure when compared with other children. As well, several parents spoke of keeping their expectations for their child open and maintaining a healthy scepticism toward the views of others, especially negative outcome prognoses.

A single mother of a young adult with a rare debilitating disease discussed the importance of acknowledging her adult child's life preferences, even though she feels apprehensive at times about his safety. "N____ loves life. He loves people. And so that's what we're focusing on; to make his life as rich and full as we possibly can. He wants to be a fireman, so he's an honourary fireman. He goes to the fire hall every week and he helps wash the trucks. They've given him a uniform. He's been skiing this year, even though he's in his wheelchair most of the time. He's been on the bobsled run. He's been in a glider plane. He went white water rafting. . . . He's driven the boat. He knows friends that have a farm and they let him drive the tractor. He ploughed through their potato patch. And he's hit the side of their barn (laughter). But those are the things he wants out of life. Sometimes when I think of the risks I have to stifle myself. But, if he really wants to do it, and he feels he can, then I think he should try."

While parents in general spoke of the importance of acceptance to managing their lives, they were frank about the difficulties involved in this process and the recurring cycles of grief that often accompany parenting a child with a disability. A mother of a child with a severe hearing impairment reflected the observations of several other parents when she commented, "Even though I say I have accepted everything that has happened with G____, yes, I have accepted it. But there are always times when I will be listening to a song and all of a sudden it will hit me, he's never going to hear that exactly like I do. And I will go through all of this again. I will go through the grieving process and I will cry. And then away I go and I'm okay. And I think this is just a life-long thing. I think it would be very wrong for me to say I can't have any more feelings about this." Thus, acceptance of a child's disability does not obliterate the expression of personal emotion. Rather, parents reported that through acceptance they were free to express their emotions without becoming entangled in self or child directed pity.

In summary, through accepting their children's disabilities the parents interviewed were able to accept life, and to come to terms with the circumstances life had brought their way. In doing so, they were also able to engage in child-focused thinking. They viewed their children first as children, not merely as disabilities or as labels. Therefore, they were also able to affirm their children's strengths in the midst of their weaknesses, acknowledge their children's preferences, and, when possible, respect their children's goals and dreams.

Sub-theme 1(b): A determination to succeed. As parents begin to reframe their attitudes toward their circumstances, many reported that they not only began to discover that managing life effectively was a possibility, they actually developed a fierce determination to do so.

The majority of parents interviewed affirmed that their determination to be as successful as possible as the parent of a child with a disability was directly related to personal choice. Several spoke of how meeting other parents who had "become martyrs and victims of their children's disabilities" enabled them not only to encounter the possibility that they, too, might become a "victim," but also to determine that they would not respond similarly. Both single and married parents linked their desire to succeed in their parenting role to personal choice. A single mother of a child with chronic multiple disabilities remarked, "You can choose to be a victim of your circumstances. There's no doubt about that. You can also choose to make the most out of what you've been given in life. . . . Ultimately we have a responsibility to our lives. There's a difference between 'putting in time' and 'making the most of it.' And it's primarily a choice." The key concept this parent shared was that she viewed her responses to life's circumstances as under her control. Though she did not choose her circumstances, she did have a choice as to how she would react to them and what she, eventually, might make of them.

While the determination to succeed usually began as a choice, it ultimately involved action. It meant a willingness to do whatever was necessary to "make it work." For eight families, 57%, that included a change of residence to a location that provided the best services for their children. Two parents interviewed also have functioned temporarily as their children's classroom aides. According to these parents, determination to be successful does not mean having all the answers or achieving goals overnight. It does mean being realistic, acknowledging that progress takes time, often a great deal of it, and being willing to persevere through many difficult periods. However, it also means aiming toward the goal of creating a family that is, in the words of one parent, "the best that we can possibly make it."

Sub-theme 1(c): Discovery of a sense of purpose or meaning in the event. Parents also reported reframing their attitudes about their circumstances by searching for purpose or meaning in them. Members of seven of the families interviewed, 50%, spoke frankly of the importance of their belief that things happen for a reason or a purpose, and that parenting a child with a disability can have benefits. A mother of a child with severe multiple disabilities remarked "There's a reason things happen. . . . I don't get into that whole thing about 'special children.' In fact, I react quite angrily to some of that 'children of God' talk and all those mythical ideas about children with disabilities. But I do believe strongly that L_____ is who she is, that she is in my life for a reason, and I try to focus on what she has given me, which is a tremendous amount."

Several parents spoke specifically of how parenting a child with a disability has positively shaped who they are as parents and individuals. The following comment was made by the mother of a child with Down syndrome. "I don't know what kind of person I might have been if I hadn't had N____. I don't often spend much time thinking about, well, what if N____ had been 'normal.' But I do spend time thinking about what would I have been like if I hadn't had N____." This mother affirmed several times that her child has made a strong, positive impact on her life.

Other parents spoke of the importance of focusing on the positive aspects of parenting a child with a disability. One parent commented, "You must not forget that there is a positive side. I think having a child with special needs forces you to dig deep and learn your own resources and learn your own strengths. It's easy to find the difficulties. . . . You do give up a lot, but you also gain a lot. I have learned to look at things from the perspective of what am I gaining in this situation."

Some parents found meaning through recognizing the influence their children have had on others. Accounts were shared of how medical personnel, teachers, classmates, relatives, and neighbours had benefitted from contact with their children. One mother of a child with Down Syndrome remarked, "Last year one of K____'s friends wouldn't go to Brownie camp unless K____ went. Her mother kept calling and asking me, 'Is K____ going?' So we learned what an important source of support K____ is to her friends. We recognized that she has a contribution to make."

Finally, for several parents, the hope that meaning would surface sometime in the future provided sufficient resources for carrying on in the present. One parent of a child with severe multiple disabilities echoed the opinion of several others with a somewhat futuristic statement. "'Why' questions often aren't answered, but having an outlook of 'where is this going to lead us?' puts a [completely different] view on things. Maybe 40 years down the road we can look back and we can say, 'Now I know why.' And usually it's because it led you somewhere." Meaning for many parents also came through experiencing personal changes which will be discussed further in the final three themes of the study.

In summary, then, half of the parents interviewed noted that part of the reframing process which enabled them to manage life effectively as parents of children with disabilities included their ability to find meaning or purpose in their circumstances. While they were loathe to think that their children were sent to them as special "gifts," they did believe that they had benefitted from parenting their special children and that their children had brought meaning to their lives and the lives of others in ways that might not have happened if their children had not been disabled.

Sub theme 1(d): Enhancing feelings of competence and self-confidence. Parents interviewed in this study reported that part of the devastation of diagnosis of disability in their children resulted from their feelings of inadequacy and inability to deal with the unique medical, educational, and daily caretaking needs of their children. Therefore, an important component of the reframing process for these parents was acquiring a sense of personal adequacy and competence as parents. When asked what advice they would give to parents of children newly diagnosed, 10 of the parents interviewed (67%) made strong statements regarding the need to acquire competence in one's ability to parent a child who is disabled.

Several parents said that they were essentially forced to acquire competence due to the lack of adequate information surrounding their child's disability and prognosis. Through keeping detailed diaries and accounts of their children's progress, they, in fact, became the experts. One parent whose daughter has a rare condition remarked that after being unable to adequately describe her daughter's seizures to a physician, she made a video tape, which has subsequently been used to educate others who work with her daughter.

Most parents described gaining competence as a process, one that gave them encouragement as they looked toward the unknown future. One mother of a child with Down syndrome remarked, "When C____ was young I used to think I had to have all the answers to his future. In time I learned that as C____ grows I will also grow and I will have the knowledge that I need to meet his challenges. It was very important for me to recognize that."

However, competence in parenting the child was only one side of the coin. Parents reported that along with competence they needed to develop a sense of self-confidence in speaking out for their child's needs. For many, this involved trusting their instincts. A parent of a child with autism recounted how a difficult preschool experience with her child was a turning point in her development of self-confidence. "The first 2 years I was myself. I was very shy and timid and I just thought that they knew what was right. But after 2 years I felt very frustrated. I used to leave there crying thinking, 'Why are you letting them do that to him and treat him like that and talk to him like that?' . . . But slowly, I developed the confidence to decide I don't have to be this way any more! Now I don't do anything anybody tells me any more at all. I do everything that I want to do. . . . Now I think there's nothing that I couldn't do if I set my mind to it (laughter)."

A number of the parents interviewed were involved as leaders in parent support groups, while others have explored educating parents and professionals through speaking and writing. These roles will be examined further in themes 3 and 7.

Sub-theme 1(e): Development of the ability to live successfully with indeterminacy. Ten parents interviewed (71%) reported inconsistencies in their children's functioning, sufficient to require changes or modifications to their daily schedules, often at a moment's notice. For these parents, developing the ability to live with indeterminacy, both with regard to daily scheduling and to plans for the future, was crucial for effective management of life. Many parents cited personal and family flexibility as an essential component of life management. A mother of a child with moderate, multiple disabilities remarked, "I guess I've learned how to just take it in stride. Most people know C____ and know that things are subject to change on short notice. I've learned to be flexible."

Living successfully with indeterminacy for many parents paradoxically meant planning ahead for those days when their daily plans would be "scrapped." A single parent of a child with a rare metabolic condition described how she made a list of things to do on "white days," which were good days, "grey days," or fussy days, and "black days," when she would have to devote the majority of her time attending to her child. The list served as an a priori reminder that while it was acceptable to go to work or even obtain respite on "white" or "grey" days, it was also permissible to order pizza on a "black" day. Other parents have described how they have learned to recognize that there will always be hurdles, to keep their commitments tentative and flexible, and to live "one day at a time."

While these parents admit that there are many things about their children's lives that they do not have control over, they do have control over how much they permit the future to dominate their present lives. One mother summed up her experiences when she wrote, "I can't say that I don't worry about what's down the road. I do, but I don't let that control how we live." While parents acknowledged that future transitions would require adjustment, they seemed to limit the ability of their concerns about the future to impact on their present lives. A mother of a child with an undiagnosed genetic condition described her reaction to the possibility of her son developing seizures. "I don't even think about it. If it happens, it will be something I'll deal with when it comes. But why worry yourself over something that could never occur?" Another mother of a child with a degenerative condition similarly remarked "And so maybe later on he'll have to have a gastronomy. But that's okay. We'll just deal with it, but there's not a darn thing they can do that will stop the deterioration. I mean, if it's going to happen it's just going to happen."

In summary, in order to manage life, many parents of children with disabilities have had to come to terms with the reality that they cannot have complete control of their lives, either at present or in the future. Accepting indeterminacy and developing strategies to live with it enable these parents to reframe their attitudes towards their circumstances and, thus, manage life more effectively. However, other strategies were also mentioned.

Theme 2: Maintain a workable balance with respect to personal roles and responsibilities. This theme examines parents' perceptions of who they are and what they do, specifically probing ways in which parents try to balance the often unique roles and responsibilities they perform as parents of children with disabilities. The following roles will be explored: (a) individual, (b) spouse, (c) parent of child with special needs, (d) parent of other children, (e) employee/employer relationships, and (f) educator of society. Though not all parents interviewed experienced every role, these roles emerged in a majority of the family situations.

Sub-theme 2(a): Individual. All parents interviewed (100%) spoke of the difficulties of finding time and energy in the midst of their busy schedules to nurture themselves. In fact, of the 14 mothers interviewed, seven (50%) recounted experiences of acute illness, depression, or physical exhaustion during their children's early years due to the excessive demands of caretaking. A mother of a child with severe, multiple disabilities remarked, "Early on I had reached a low, a real low. I wasn't coping well. I wasn't sleeping well. I was just continually worried about M____. I was getting up at night. I had to turn him over to clear his chest. It was 24-hour care. I realized I needed some help, but I didn't know how to go about it." Another mother described a similar experience. "I had to hit bottom before I picked myself up. Because I went through a really bad year when I just gave up. . . . Everyone thought I was having a nervous breakdown. I didn't want to get out of bed; and I didn't want to see anybody. And I didn't want to go downstairs because I knew I'd have to deal with the [children]." Mothers commented that they felt their days were not long enough and that it was difficult, especially during the early years, to find time for themselves.

However, despite the difficulties, all mothers interviewed stressed the importance of carving out time for themselves. Strategies they found effective included getting away, developing other hobbies or interests, investing in at least one supportive friendship, and engaging in physical recreation. Eight of the parents interviewed (53%) reported that their most important personal coping strategy was to get away, either by themselves or with others. For many mothers one outing a week was important. A mother of three children with disabilities commented, "I have one night a week that's mine. I need it. I forget about everything for that evening and go out with my girlfriends. I know none of them can relate to what I go through. They have stress and they have 'normal' kids. If they need a night out once a week, I probably need three! But yes, I just go out and try not to worry about anything that night and somehow the next day doesn't seem as bad." One mother made an interesting comment about personal respite. "Getting away is important, but I don't [actually] have to get away. I do have to know that it's possible, if I want to."

Getting away for an extended period at least once a year was considered by many mothers necessary for restoring physical equilibrium. One mother remarked, "We've had a lot of difficulties and I'm certainly not saying that things have been easy, because they haven't. It's very demanding. I'm very tired. And I've certainly had some significant health problems, because of all the demands. And it's constant. But that's why I've learned to take the breaks to take care of myself. And once a year I go away by myself. Last December I flew out to Vancouver . . . and I felt like a new person when I came back."

While several mothers spoke of the need to overcome guilt about taking time for themselves, they suggested that if they neglected their own health, they would be less capable of caring for their children. Especially difficult for some parents is walking out the door during a moment of turmoil. However, as one mother commented with a laugh, "Once you do it you realize they're still there when you get back." Probably the most common advice these mothers would give to parents of children newly diagnosed concerning respite is a resounding "just do it."

A number of parents also spoke of the need to deal with negative emotions, such as anger or negative thoughts toward their children. Several parents stressed the importance of acknowledging that these thoughts and feelings are normal, and of being able to discuss them with others, such as spouses, other parents, doctors, or friends. For a number of these parents, the presence of at least one close friend in their lives was significant. Friends provided encouragement, information and feedback regarding parenting skills, a normalizing perspective of family life, and personal nurturance.

At the same time, some parents cautioned against overburdening their friends with chronic problems and then expecting these same friends to constantly buoy them up. A single parent of a child with an undiagnosed metabolic condition stated, "Sometimes I don't share [my difficulties] with L____ any more, because I don't want to. Because when it's chronic in nature, it's the same old thing. It's a difficult behaviour. It's another illness. It's another problem. Year after year after year." She realized that one important function of her friends was to provide a measure of emotional respite from constantly thinking about her child's needs. Her friends brought other interest areas into her life that supplied needed and welcome balance.

Finally, many parents found balance in their lives through staying involved in interests and hobbies, volunteering or working outside the home, and keeping physically fit. These parents expressed the idea that if you want to give something to another, you have to have something to give, and that through nurturing themselves they, in turn, were able to more adequately nurture others, especially their children with disabilities.

Sub-theme 2(b): Spouse. Twelve (80%) of the parents interviewed were married. These parents spoke frankly about some of the difficulties they have experienced in their marriages. Major difficulties seemed to relate to issues of time, such as getting away together, and role imbalance, especially with regard to decision-making and childcare responsibilities. While several parents affirmed that their marriages have emerged stronger as a result of parenting a child with a disability, one woman observed somewhat disconsolately that through the years she and her husband had "grown apart." Two parents stated that they and their spouses sought professional marital counselling, which was helpful; and others remarked that they had to learn to talk openly with their spouses, work together as a team, share responsibilities satisfactorily, and respect their spouse's ways of coping. Interestingly, of the 12 married parents interviewed, 10 (83%) stated that their spouses used quite different coping strategies than they used, a situation that necessitated some adjustment and acceptance.

For the majority of married parents interviewed (92%) creating and sustaining a strong marriage was extremely important to managing life. While sharing responsibilities was important to these parents, the real issue was not so much equal division of responsibility as it was joint ownership and accountability. In fact, many of these parents described a rather unbalanced division of labour regarding their child's special needs. However, the variables that made each situation successful were that the division of labour was jointly agreed upon and satisfactory to both partners, and that the less involved partner was able and willing to help with such things as practising signing, performing chest physiotherapy, or attending a school meeting or a medical appointment as the need arose.

Parents often described being at different emotional levels than their spouses. While several related that it has been important to recognize and permit a spouse to express frustrations and negative emotions, the fact that one parent might feel "down" when another is "up" can be helpful for overall marital stability and can over time create a complementary dyadic balance.

Similar to finding time for self, finding time to get away together was described as one of the more difficult yet important ways of maintaining a strong marriage. While for many couples getting away was nearly impossible in the first several years of the child's life, couples that did make a point of getting away contend that their marriages in general were healthier. One mother's advice to parents of children newly diagnosed was, "Get some help and use that relief if you can. Get away together and get a rest. You see things differently. You feel a little bit better. You stay connected with one another."

When marriages failed, parents spoke of the need to resolve successfully emotions such as anger and guilt, and feelings of abandonment, simultaneously with creating opportunities for the other parent to remain involved with their children. Of the three single mothers interviewed, two indicated that their former spouses have little or no contact with their children, while the other remarked that her former husband is just beginning to be involved in his child's life after an absence of approximately 18 years. Despite the difficulties of being single mothers, these parents have all affirmed positive outcomes and one has gone on to foster 11 additional children.

As one parent said, "Your marriage is foundational to everything else." The majority of the parents interviewed have found that nurturing their marriages and building stronger relationships with their spouses has enabled them to manage their lives more effectively.

Sub-theme 2(c): Parent of a child with special needs. Many parents commented that parenting a child with special needs brought with it three different roles: parent, teacher, and advocate. One expectation most parents interviewed discovered soon after diagnosis was that they were required to become in some way their child's teacher or therapist. While for most parents this involvement enabled them to feel as if they were "doing something valuable to help" their children, there were times when the expectations were overwhelming. Many parents interviewed spoke of the need to set limits regarding the expectations placed on them by others and to make their primary goal that of being the child's parent. For some this was a decision made over time.

"When we found out G____ was hearing impaired and started coming here and got all this information on how to work with him, I all of a sudden turned into his teacher instead of his mother. . . . But finally a few years ago, I just woke up and said, 'No, I'm not doing all this. I am just going to practice being his mother.' And I am much happier. I feel it was like a weight lifted off me." This comment was echoed by several other parents, some of whom now caution parents of children newly diagnosed to avoid falling into what was for them a "trap of expectations."

Several parents interviewed also spoke of their goals for their children, such as integration into the school and the community, being happy, achieving their potential, having a productive life, and experiencing friendships. Many times these goals required parents to become advocates on behalf of their children. Advocacy for some parents was a process of trial and error and many described themselves as still in the learning stages. Probably the most frequently cited need for advocacy centred around the child's educational placement. Eight of the parents interviewed (53%) had children in fully integrated programs. Four others (27%) had children in programs of partial inclusion. Achieving placement in these programs required substantial intervention on the part of several of these parents. One mother of a child with autism who is partially integrated stressed the importance of advocating on the terms set forth by the local school board or agency. "Before I even started my negotiations with the Catholic board, I pulled out their mission statement. It says 'Every child has the right to dignity, respect, and an education.' Well, I thought, my child falls into that 'every child' category."

Another parent noted that being an advocate is a continuing process that involves annual discussions of classroom and teacher assignments and adequate support systems. Especially difficult are times of transition, such as moving from elementary to junior high school, or changes in educational administration at the local school or district level. More than one of the parents confessed that they had challenged an issue right up to the office of the Provincial Minister of Education.

Several parents admitted that as a result of their efforts to advocate for their child, they have been labelled a "difficult parent." To combat that perception, many of these parents stay involved in their local schools and participate in their children's classrooms. Parents also stressed that while they do not expect to find "the perfect program" for their children, they do expect their local schools to be at least partially inclusive and to provide programming suitable to their child's needs.

Balancing the roles of parent, teacher, and advocate can be very challenging. These parents' advice to others is to know yourself, state clearly to yourself and others what you want to be involved in or to avoid, set limits on outside expectations, and prudently guard the role of parent. As one mother commented, "Your child will have lots of teachers and therapists. He will only ever have two parents."

Sub-theme 2(d): Parents of other children. Of the 14 families who participated in this study, 12 (86%) consisted of two or more children (mean of 3.3 children in these families). In seven of the 12 families (58%) the child with disabilities was the firstborn child. Several of the parents interviewed spoke frankly of some of the difficulties they faced as they attempted to balance time and energy among their children. Parents shared their feelings of guilt concerning lack of equal time with their nondisabled children, cheating their "normal" children out of a full childhood, or minimizing their other children's concerns. One mother whose firstborn child was developmentally delayed talked about her middle child's earlier responses. "When the second, B____, was born, we didn't know yet what was going on with C____. And I was running around dragging this baby here, there and everywhere while we were at meetings and getting things finalized. When she was 18 months she was sitting in her high chair and her first complete sentence was, 'I'm going to run away from home.' I think it's because she felt that we were pushing her aside a lot." Another mother in a similar situation also remarked of her second born, "I know I made her grow up faster. And I think it was very unfair to her, very unfair. She really did not have a chance to be a baby. She's now 9, going on about 40. But I think that's my fault, and I do feel very guilty about that."

Some parents related how they attempted through the years to compensate their nondisabled children by enabling them to have experiences they might not have had, for example, trips, concerts, involvement in activities, or special camping adventures. Several of the parents spoke of the importance of spending respite time together both at home and away, in order to give their nondisabled children their total attention. As well, these parents have tried to stay involved in their nondisabled children's activities, though for many parents undisrupted periods of time have been difficult to find. In spite of these attempts toward "equalization," a major frustration for many of these parents continues to be appropriate and fair divisions of time.

While not negating the difficulties some of their "severely normal" children face as siblings of children with disabilities, such as embarrassment, being teased by others, and anger toward the disabled brother or sister, many parents spoke of the benefits their children have experienced. Many described their children as more knowledgable, more sensitive, more caring, and more tolerant of other people. As well, their nondisabled children have developed their own unique skills at negotiation and advocacy, not only for the benefit of their brothers and sisters but also to assist others outside the family. One mother whose children are now young adults described how, though there were some very difficult years initially, her sons are now quite close, share a house together, and are being enriched through their friendship.

Parents remarked quite emphatically that though they hoped their children would develop a close sense of family, they did not want their nondisabled children to feel completely obligated to care for their siblings in the future. A mother of a child with Down syndrome commented, "We want them to grow up and feel good about being sisters. We want them to feel they're responsible to one another, but not as a burden or an obligation. We want them to do that because they're siblings, not because K____ has a disability."

There is no doubt that parents of children with disabilities involved in this study struggled at times with issues surrounding the division of time and energy among their children. The unique ways in which they have learned to affirm and respect all their children, while acknowledging up front that the distribution of their time and energy might be unequal, has enabled these parents to manage their family lives more effectively.

Sub-theme 2(e): Employer/Employee Relationships. Of the 15 parents interviewed, nine (60%) were employed either full- or part-time. Two other parents were heavily involved in volunteer work. Several parents spoke of their work as being somewhat therapeutic due to the personal enrichment they received through it, the opportunity work provided to promote and utilize their skills and interests, and the diversion it afforded from childcare issues. A parent of a child with pervasive developmental delay commented, "I just went to work and could forget about everything for 8 1/2 hours every day. So that took a lot of the pressure off. I don't know if that's good or not, but it's probably effective."

Through interacting with co-workers, parents interviewed stated that they were better able to normalize many of their own personal and family experiences. While most described their employers as supportive, several remarked that they or their spouses had to go through a number of job changes to find supportive employment situations. By far the three most important issues surrounding employment for these parents were schedule flexibility, accommodating childcare arrangements, and personal fatigue factors. However, the parents interviewed who did work related that their employment, for the most part, produced beneficial life outcomes.

Sub-theme 2(f): Educator of society. Several of the parents spoke of issues concerning their family's relationship to society, such as feeling different, being discriminated against, or finding services in their communities inadequate for their families' use. Parents expressed varying views concerning their responsibility for educating people about their child's disability or about disability in general. One mother commented, "I feel as if I have to be a teacher constantly." However, another countered, "We have too many parents who say, 'Well, I should stop and explain.' I said, 'No, you don't owe the world an explanation.' There are certain times when we do come into situations where it's a wonderful opportunity to do some public awareness. But it's not every time your child does something."

A number of the parents interviewed have been involved in public education by representing a variety of agencies, schools, and hospitals at public events. Others have spoken to meetings attended by educators, social workers, or medical personnel. Several have written articles that have been published by newspapers, or distributed in book or pamphlet format. They have also crusaded to obtain changes to public buildings, such as inclusion of appropriate washroom facilities, ramps, or doors that permit wheelchair access. While many of these parents realize that parenting a child with a disability often requires them to be educators of society, they have worked to integrate this responsibility with a level of involvement that conforms to their personal preferences and aptitudes.

Theme 3: Ability to meet personal, child, and family needs by locating and utilizing resources effectively. Parents who have a child with a disability often require resources and supports beyond the capabilities of their immediate or extended families. Parents included in this study cited a number of resources which have enabled them to manage life effectively, such as gathering information, collaborating with professionals, connecting with other parents and parent support groups, and utilizing other sources of support. Again, as will be seen, not everyone included in the study utilized every resource category. However, the categories included in the analysis were mentioned by the majority of interviewees.

Sub-theme 3(a): Gathering information. As was stated earlier, lack of information concerning their children's disabilities was frustrating for most parents interviewed. Therefore, many parents set out to learn, often on their own, as much as they could about their child's specific handicap. One mother commented, "[Getting information] was my focus. I became obsessed. I had to find out everything there was to find out about autism, from wherever I could find out." Another mother described herself as "hungry for information." In fact, parents representing nine (64%) of the families included in the study reported that searching for information about their child's condition was one of their first responses to diagnosis.

In order to find information parents visited libraries, attended conferences and meetings sponsored by various societies representing persons with disabilities, networked through parent groups, subscribed to magazines, and conferred with medical personnel. A frustration for many of these parents was the paucity of information available. A mother of a child with a degenerative condition remarked, "I think that the lack of information that families are given, the cursory nature, the slanted nature, or the biased nature of the information that is given puts pressure on people to make decisions that maybe later on they aren't comfortable with."

Because four of the children of parents involved in the study have rare or as yet undiagnosed conditions, these parents, through their own recording of information regarding their children's progress through the years, have become quite knowledgable about these rare conditions. However, several of these parents also reported that they have chosen to put limits around the quantity or category of information they are given. A parent of a child with a rare metabolic condition remarked, "If I look at the big picture with L____, it's a very difficult picture. And I don't like to look at it. I don't choose to look at it. I choose to deal with bits and pieces at a time. I mean, there are many unknowns. I have no idea in terms of prognosis. So, I just have to look at the progress she's making at present."

In summary, while locating helpful information about their child's disability is important to parents, parents may also choose to limit the amount or type of information they access, especially as it relates to negative outcomes. As well, parents realize that their child and his or her surrounding circumstances are unique and general information may not directly apply to their family situations.

Sub-theme 3(b): Collaborating with professionals. Parents of children with disabilities often have greater contact with a more diverse number of professionals, including health care, government and social services, educational, and home maintenance personnel than other parents. While many of these relationships are beneficial, 13 of the 15 parents interviewed (87%) reported unnecessary and unwarranted frustrations with professionals or, what many called, the "bureaucratic system." A mother of a child with a rare degenerative disorder stated frankly, "The challenge really around N____ has not been N____. It's been system stuff. When you have a child who has a label of being mentally handicapped and you have to take on these giant systems that are so entrenched and rigid, it takes so darn much time. Half of your life is spent just trying to convince people."

Major frustrations parents reported involved issues such as long waits for referrals, conflicting, inadequate or confusing medical diagnoses, focus on negatives instead of a more holistic approach, insensitivity toward parents or children, and lack of time with professionals. One parent of a child with multiple disabilities related what for many parents was a recurring experience. "Just going to the [clinic] is one of the worst experiences most parents have. Everything just takes so long and costs so much. And for a hospital that's supposed to be geared toward rehabilitation, it doesn't make a whole lot of sense. At the prosthetics desk there's a little sign that says 'If you are 15 minutes late or more for your appointment, consider that it might be cancelled.' Then I think, most of us come here with children who are in wheelchairs. It's difficult to find a parking spot. Why can't a hospital like yours be understanding? Then we go and we usually wait an hour." Another mother added, "I wish just once they'd say, 'You got here.

Congratulations.' And pat me on the back."

Not only can frustration with professionals and the system run quite deep, it can also have a cumulative effect on parents who may grow very cynical toward the people and organizations that are trained to help them. A mother of a child with autism summed up her experiences with professionals with a rather sobering statement. "If I were to look back, of all the people we have met, there wasn't one professional along the way who I can say I felt a whole lot of support from in anything I did. And as a parent you often need a professional to say, 'You're doing really well.' Never. I think they all had a fear of this child, probably because they didn't have any answers."

While the topic of professionals generated a good number of negative comments from the parents interviewed, there was also indication from many that some of their strongest supporters have been those professionals who have provided them with information and support. Parents described helpful professionals as those who had time to discuss parental concerns, were honest, gave encouragement, affirmation and hope even in the bleakest hours, allowed parents to express their emotions and to realize that these emotions were normal, helped parents discover their strengths, showed an openness to alternatives, and had knowledge of additional sources of support.

Several parents acknowledged that over the years they have developed more competence with regard to collaborating with professionals. Skills such as being honest and open, stating clearly what information and assistance are needed, supporting and appreciating what professionals can offer, not expecting professionals to have all the answers, and viewing the parent/professional relationship as a partnership have enabled these parents to work more effectively with the professionals involved in their children's lives. One parent remarked, "Not only must you put yourself in your child's shoes, you must put yourself in the shoes of the professional as well. . . . I've found, if you watch what you're saying when you approach people who are working with your child, usually I find, about 95% of the time, you'll get cooperation, because most people are willing to say, 'Okay, give me some ideas for how I'm going to work with this kid.'" As well, parents stated that while they often attend meetings with a strong sense of what they want for their child, they must be willing to "make trade offs and perhaps let some issues go altogether" in order to maintain a functional and practical working relationship with professionals. Though these parents are well aware of the deficiencies in the parent/professional relationship, they have learned to extract and to utilize information that is valuable. At the same time, several commented that they have also learned to maintain a "healthy scepticism" concerning information given by professionals.

Sub-theme 3(c): Connecting with other parents or parent support groups. Parents representing 12 of the 14 families included in this study, 86%, stated that contact with other parents of children with disabilities has been one of the most important contributors to their management of life. Several stated that contact with another parent facilitated a turning point in their own ability to appraise or reframe their circumstances. A parent of a child with Down syndrome remarked, "For me, the difference was talking to another parent. Just to see that another family was coping and that they could laugh and smile about things. It was like there was a weight lifted off my shoulders, and I thought, 'life goes on.'"

Parents interviewed stated that other parents acted as role models, shared family life and child care strategies, gave hope, encouragement, and affirmation, understood frustrations, and shared their joys and sorrows. Parents also remarked that other parents keep them accountable. One mother noted, "You can't fool another parent. They can see right through you. And that's good, because it's important, it's crucial, to have someone who keeps you honest."

Many parents stated that in times of difficulty, the people that they turn to most often are not professionals, but other parents of children with disabilities. The mother of a child with severe hearing impairment remarked, "There's something that draws us all together. If I'm having difficulty with something, I will call another family and ask 'How did you deal with this?' or just cry. And on the other end you can just feel the hugs coming across the telephone. And that's so terribly important."

Parents who did not have contact with other parents during their children's early years reported feeling a loss. A good number of them stressed the importance of putting parents of children newly diagnosed in contact with appropriate parent groups as soon as possible after diagnosis is made. While these parents may need time to adjust prior to initiating or following up on contact with the group, having the information at hand may enable more parents to realize that there are others who understand.

Sub-theme 3(d): Utilizing other sources of support. Many parents interviewed cited other important sources of support, such as extended family members, community, church, and in-home childcare services. While none of these categories contained a majority of the interviewees, their importance for those who utilized them renders examination of these supports essential to understanding successful life management for these families.

Parents representing six of the families involved in the study (43%) stated that assistance from extended family members has been an important component of life management. Extended family members supported these parents by affirming parents' decisions, visiting the child in hospital, accompanying parents to appointments, babysitting and providing respite, transporting the child to school or therapy, normalizing difficult experiences, celebrating the child's progress, and accepting the child for who he or she is.

However, not all parents found extended family members completely supportive. Some stated that because extended family members resided at some distance, they were generally ignorant of the issues surrounding their children and did not have the necessary skills or familiarity to communicate with them. Others commented that support from extended family members was fairly inconsistent and communication was at times strained because extended family members were often at different points with regard to issues such as acceptance and access to information. A mother of a child with a rare, metabolic condition stated, "When there's a hospitalization you always have people there. It's when you get home and you need the support that it drops off. A lot of people don't understand chronic illness and disability. They don't know how to be supportive." A parent of three children with multiple disabilities added, "Everyone was around at the beginning. But once the girls started getting older, and when we needed lots of help, it seemed like not so many people were around any more. I think it was fear. . . . But part of it was our fault, because we don't bring the children to a lot of family functions. It's too much work. And when we bring them I end up doing everything and I don't enjoy the visits. So, it's like they don't really know what [my children] are about any more." Just the same, parents often reported that even in families where extended family members are largely unsupportive, there usually are one or two people who provide encouragement and assistance.

Five of the parents interviewed (36%) mentioned that their communities or members of the neighbourhood were an important resource for managing life. Friends and neighbours have contributed by babysitting, supplying food, assisting the family during a child's hospitalization, taking the family's other children on outings, and supporting an inclusive environment both in community clubs and through the local schools. One parent commented on how the affirmations of other parents in the community have enabled her to value her child. "Other parents will come up and say, 'Gee, I'm glad N____ was in our Cubs.' or 'I'm sure glad N____ came on the field trip.' You get positive feedback and that energizes you.

Sometimes when it's hard for you to find something positive in your child, somebody will come up and say something. And it's having other people tell you that sometimes helps you see it." Several of the parents spoke of the need to establish within residents of communities a greater sense of ownership and responsibility for individual members of the community. As one mother responded, "Communities need to recover the lost art of pitching in and helping out."

Six of the parents interviewed (43%) mentioned receiving meaningful assistance from their churches. Similar to help from communities, members of churches provided services such as babysitting, food, clothing, counselling, assistance with the child's therapy, and support through prayer. A mother of a child with pervasive developmental delay remarked that families in the church she attended made her child feel included at times when others seemed to be avoiding him. Another mother of a child who was flown to a distant city for diagnostic tests related the way in which members of a local church in that city supported during her brief time there. The kindness she felt from the congregation was so radical, she remarked, "Actually, when we came back, I realized that it wasn't C____ who had had the healing. It was me. I never had anyone surround me with love like that."

Finally, four of the parents (29%) described the importance of in-home child care and housekeeping services. While these services were invaluable, they also brought incumbent stresses. One mother spoke of the difficulties associated with being an "employer" and another mother who has several children with disabilities added that she felt as if she "coordinated a group home."

Parents related that support is crucial because though support does not erase the pain involved with parenting a child with special needs, support "spreads out the work." They also acknowledged that types of support vary from person to person and situation to situation, and that their own networks of support have changed, sometimes considerably, over time.

In summary, parents of children with disabilities interviewed utilized the following strategies to manage life more effectively. First, they reframed their initial feelings of devastation concerning the diagnosis of disability in their children by accepting their children as they are, developing a determination to succeed, discovering a sense of purpose or meaning in their circumstances, acquiring competence and self-confidence in the skills needed to parent their child, and learning to live with indeterminacy. Secondly, parents who managed life effectively endeavoured to maintain a workable balance with respect to their various roles (who they are) and responsibilities (what they do). Finally, parents learned to locate and utilize resources productively.

If the goal of question one was to ascertain what parents of children with disabilities do to manage life, the goal of question two was to discover what these parents are like. It is to this question that attention is now directed.

Question 2: Is it possible to identify personal attributes or abilities that characterize parents who manage life effectively?

The focus of this second question is parental characteristics, or those attributes or abilities that parents of children with disabilities either possess or view as important for effective management of life to occur. Parents interviewed were asked to identify from their own experiences the traits that were most important to their ability to function proficiently. The three themes that emerged in response to this question were (a) personal character traits of parents who manage life successfully, (b) decision-making and problem-solving ability, and (c) personal or family philosophy of life.

Theme 4: Personal character traits. Six character traits were mentioned by at least one half or more of the respondents. These major character traits were flexibility, patience, persistence or determination, positive outlook, sense of humour, and willingness to accept help. Other character traits mentioned less frequently included willingness to grow, learn, or change, self-sacrifice, self-awareness, straight-forwardness, and unconditional love. While some parents recognized that they possessed these attributes to some degree prior to the birth of their child with special needs, most remarked that parenting a child with a disability required them to develop and employ these traits to a greater degree than was necessary with their other children.

Both parents of children with autism affirmed that patience and flexibility were essential for effective life management. One of the mothers responded, "Patience. Patience is the thing that overrules. And second is flexibility. . . . Autistic kids very much need structure. But within those structure confines there has to be flexibility, . . . because you have to be prepared to change your plans at any time." The other parent corroborated, "Flexibility is key. . . . But at the same time you're probably running a tighter routine than you ever have run before."

Other parents mentioned persistence or determination as an essential parental characteristic. These parents stressed that a strong conviction that they knew what was right for their children and a steadfast determination to carry out their plans as much as possible has been essential for managing life. Several parents suggested that persistence included an ability to keep asking questions, often the same questions, until they had answers that were comprehensible and useful for decision-making purposes.

Similar to the need to reframe their attitudes about the facts and their feelings surrounding their circumstances, over half of the parents interviewed confirmed that a positive outlook, or positive thinking, was important to successful life management. Parents emphasized the positive aspects of their situations as they spoke of learning to turn negatives into positives, "training" themselves to dwell on the positives, or assuming an attitude of "it could have been worse." For many, positive thinking was a learned attribute. A mother of a child with Down syndrome shared how a behaviour support specialist helped her become a more positive thinker. "One of the things the behaviour support team did with me is they put me on a program for positive reinforcement of N____. Because I went through a time when I'd go for days and I couldn't think of one positive thing to say about him. It was very stressful. He would disappear. He was very, very aggressive with his younger siblings, and it was a difficult time. So they put me on a positive program where a little buzzer went off every 15 minutes and I had to say something positive, like, 'N____, you're sitting so nicely in front of the TV,' or 'N____, that's a nice shirt you picked out today.' And that was another turning point. Because you can get into negative ways of talking about and thinking about your children." Parents also spoke of the need to avoid contact with people, even family members, whose negativity discouraged them.

Having a sense of humour also enabled many parents to manage life more effectively. Humour tended to bind family members together, provide a release from some of the more painful tensions associated with parenting a child with a disability, and enable parents to reinterpret difficult or embarrassing circumstances. A mother of a child with severe, multiple disabilities commented, "Yes, we joke about it. Because part of coping is just to learn to laugh. You feel, 'We've got the pain. We can laugh, too.'" Another mother echoed, "It's pretty important to be able to laugh. And lots of families have their little stories that they tell and retell. The N____ stories in our family are the funniest. I mean, he is just hilarious. But for every funny story you probably have about 10 or 20 difficult stories. Stories of challenges and trials and that sort of thing. But it's the funny stories that keep you going."

Finally, a majority of the parents interviewed cited willingness to accept help as an important characteristic of parents who manage life effectively. All parents interviewed spoke of the need to acknowledge that they "could not do it alone." For many, this was a difficult acknowledgement. A single parent commented, "At times it was very challenging. But one of the things that I think it did for us was that I realized early on that I couldn't manage all of this by myself. And so I invited people into our lives. From that perspective I think it was very positive." In fact, 10 (71%) of the parents interviewed gave accounts of personal struggle or crisis situations culminating in accessing some kind of support that enabled them to manage life more effectively. Many now view their ability to reach out to others as a strength.

While parents were often quick to identify these six characteristics as important to successful life management, they certainly did not perceive of themselves as always proficient or consistent at displaying them. Rather, they spoke of themselves as "learners" who recognized the value of these traits and who were attempting to incorporate them into their own lives. They stressed the ways in which other parents of children with disabilities have modelled these traits and encouraged them to stay flexible, be patient, focus on the positives, remain persistent, maintain a sense of humour, and accept help from others.

Theme 5: Decision-making and problem-solving ability. Twelve of the 15 parents interviewed (80%) confirmed that having a strategy for confronting problems and making decisions has contributed to their ability to manage life more effectively. Parents cited various aspects of decision-making such as ownership or control, exploring options creatively, including the child when possible, and implementing strategies as crucial to constructive decision-making. Ownership or control of the decision-making process was the component parents reflected on most often. Ownership for most of these parents involved becoming primary players in the decision-making process, upholding family and personal values over the opinions of others, and assuming responsibility for outcomes associated with their decisions. For many parents, the impetus to take ownership followed a difficult experience. However, parents commented that while the anger that resulted from a difficult experience might propel them to take ownership, they tried to maintain a spirit of diplomacy in their interactions with others. A mother of a son with a degenerative condition commented, "I think that the ability to problem-solve is a very valuable one, because a lot of times the 'no' is a 'no' because they think you're going to go away. What you need to do is try to analyze the situation in a way that you will get what you need in terms of your son or daughter, but not in a manipulative way. I think if you do your homework and are well prepared and can make a legitimate argument, that often people will listen. And the anger that maybe propels you to do that, I think, needs to be controlled to some extent when you are presenting." For some parents, ownership meant going against the counsel of others, a decision that often required a great deal of confidence and personal strength.

Several parents stressed that when situations developed in their children's lives that were distressing or troublesome, their best response was to creatively explore all the possible solutions. For some, this was a confusing and complicating procedure, especially if they felt that professionals in "the system" had already determined what options would remain negotiable. One method that many found helpful, though, was to include the child when possible in the decision-making procedure. Though children might not always be present at more formal procedures, these parents felt strongly that their children's voices and preferences needed to be heard and respected by all who were involved in the decision-making process.

Finally, several parents spoke of the importance of ensuring that decisions would be acted upon. Arriving at a decision does not always guarantee its implementation. Rather, implementation may involve dogged persistence on the part of parents and family members. A number of parents described how they had to "push" to get services like referrals for medical assessments, classroom aides to enable their children to be integrated, or necessary equipment for their children's use in the home or at school. Several parents spoke frankly about some of the mistakes they had made through the years. However, they stressed the importance of recognizing that as parents and advocates they are not perfect, and that, in the end, most decisions can be kept fluid and modifiable. One parent commented, "Sometimes as parents of children with disabilities we're faced with difficult choices. I can't say I've never made a mistake, because I have. Lots of them. But I try not to make them a second time and I give myself credit for what I've learned."

Parents of children with disabilities who have strong decision-making skills that involve taking control or ownership of the decisions made, exploring options carefully, including the child when possible in the decision-making process, and following through to see that decisions are implemented, are able to more effectively manage their lives and their families. While some parents spoke frankly about the mistakes they had made through the years and referred to themselves as "learners," many acknowledged that their growing competence in decision-making enabled them to shape more actively the ways in which their families function.

Theme 6: Philosophy of life. Twelve of the parents interviewed (80%) reported receiving personal strength from strong inner convictions. Many referred to this as a type of "spirituality," whether defined as the existential search for purpose or meaning, or the transcendent reliance on a higher power. For some parents, spirituality provided an answer to the reason or purpose behind their circumstances and affirmed the potential of suffering to produce positive results in their lives. One mother contemplated, "I always say, it's only out of adversity that you learn strengths. If your life was a piece of cake every day, why would you need to learn anything? It's only in the face of adversity that we learn where our strengths come from."

Other parents, however, verbalized a more matter-of-fact philosophy of life. A parent of a child with autism encapsulated the feelings of several others with a rather stoical statement. "My husband and I came to acceptance very quickly. We didn't grieve for a long time, I don't think. We sort of figured, well, this is what we have to do, so let's get on with it." Parents recognized the danger of getting stuck in the quagmire of asking "Why?" One parent commented, "We have parents who get past the diagnosis, but then sort of get stuck in that 'Why?' phase. We have a Dad who sits and pores over one of our medical journals. . . . But I just think different things happen to us. I don't think there's always a reason." For some parents, acceptance of the fact that there may not be a specific reason or a purpose for things that happen to them enables them to become reconciled to what one parent described as "a random act of nature."

Nonetheless, for seven of the 15 parents interviewed (47%) reliance on personal faith in a transcendent God has been an important resource for interpreting and managing their lives. One mother reported, "[Faith in God] doesn't always make it easier, but it brings perspective. I really do think that having faith or a spiritual life has been really one of the best benefits I could have had. . . . If someone had told me 18 or 19 years ago that I was going to have this handicapped child and have to deal with it I would have said I couldn't have done it. But when I stop and think about everything that I do and what I accomplish in the course of every day, I couldn't do that by myself. I have to have been given the strength and I'm sure that it's divine strength that I've been given in order to cope." Several parents also spoke of the encouragement that the faith and prayers of others has been to them personally.

While some parents described themselves as possessing a particular philosophical or spiritual approach to life prior to the diagnosis of their child's disability, others described their current belief system as being gradually and progressively shaped through their parenting experiences. However, for 80% of the parents interviewed, the inner convictions and beliefs that formed their personal philosophy of life were an integral component of life management.

In summary, parents interviewed who manage life effectively are people who value and cultivate such personal character traits as patience, flexibility, a positive outlook, persistence, sense of humour, and a willingness to accept help. They are also people who have developed strong problem-solving skills, especially with respect to taking ownership of a situation, exploring options and solutions, and implementing strategies. Finally, they are people who receive personal strength from strong inner convictions.

Question 3: Is it possible to extract a common theme or themes describing how parents are transformed through their parenting experiences? The intention of this third question was to probe ways in which parents of children with disabilities have experienced positive or beneficial outcomes through their parenting experiences. Parents interviewed spoke of undergoing positive changes in who they are, how they relate to others, and how they look at life. Therefore, the three themes which have emerged from the analysis are (a) personal transformations, (b) relational transformations, and (c) perspectival transformations.

Theme 7: Personal transformations. This theme focuses on parents' expressions of beneficial personal change as a result of parenting a child with a disability. While every parent interviewed shared at least one personal transformation, most expressed several ways in which they have been individually enriched. Personal transformations clustered into two sub-themes: acquired roles and acquired traits.

Sub-theme 7(a): Acquired roles. Twelve of the 15 parents interviewed (80%) had acquired at least one role that had resulted in a beneficial change in their lives. Most commonly parents spoke of their new roles as parent group leaders, conference speakers, advocates, teachers, writers, or members of advisory councils for schools, hospitals or agencies representing persons with disabilities. A mother of a child with Down syndrome remarked, "C____ has helped me find a side of myself I didn't know existed. I went from seeing myself as not having a lot to give the world to having a new world open up to me--a world of advocacy. Before I felt voiceless. But then I recognized [my child] is voiceless. I am the only voice he has. . . . Advocacy for others is now an important part of my life. So I have come to discover new pieces of who I am through C____." Another parent spoke similarly of new roles in her life. "I've been changed. I've had opportunities I never would have dreamed possible by being involved in advocacy in terms of going to international conferences and being asked to speak at different conferences and share our story. So, I think that for me personally, 'enriched' isn't really a large enough word."

Taking on a new role has not always come naturally to some of these parents. One mother of a child with autism described how getting answers for herself and others required her to assume a new role in her parent group which resulted in positive personal growth. "I never, ever saw myself in a leadership role or ever as a president of something, because I was usually quiet and submissive.

But I felt there was such a strong need. So I got some information and began to piece a group together. Now I'm president of that group. So, yes, I changed quite a lot as a person."

Parents reported that in order for beneficial outcomes to occur they had to be willing to change and to focus on possibilities in the midst of the negative aspects of their circumstances. Overcoming difficulties in their lives often provided the impetus for positive personal transformations to occur.

Sub-theme 7(b): Acquired traits. Many parents not only assumed new roles, they acquired new, or extended existing, personal traits. Parents spoke of becoming more compassionate and less self-focused, learning that they could achieve rather than remain powerless, developing endurance or greater personal strength in the midst of their feelings of weakness, progressing from depression to being able to view all life as worthwhile and of value, and facing life with a new boldness rather than capitulating to fear.

For many of these parents, discovery of these inner personal traits was largely unanticipated. One mother commented, "It's taught me I can achieve. And that I have endurance. I have strength. I never thought I had those things." Another added, "I'm way more outgoing. And I laugh more now. I take a lot of things less seriously." Along with the acquisition of new personal traits was the development in many parents of a stronger sense of self-respect. One mother commented, "As I learned that C____ was worthwhile, I learned that I was worthwhile, too."

Parents described personal transformations through the acquisition of new roles and the development or extension of personal character traits. While parents themselves have been personally enriched through these transformations, they also acknowledged that personal transformations interrelated closely with perspectival and relational transformations.

Theme 8: Relational transformations. Relational transformations refer to changes in the ways parents of children with disabilities relate to other people. Thirteen of the 15 parents interviewed (87%) described at least one positive relational transformation as the result of parenting a child with a disability. Relational transformations included statements about immediate family members, friendship networks, attitudes toward people in general, and situations arising out of advocacy.

Six of the married parents interviewed (50%) reported that their marriages were stronger than they were prior to the child's diagnosis. Some of these parents reported having marital difficulties initially; however, the need to find solutions to often complex situations required a number of these couples to improve their existing communication skills and to reinforce their marriages. While other parents did not describe their marriages as necessarily stronger, they did stress that they had to learn to talk more openly with one another, listen to each other's concerns, and give each other physical and emotional support.

Several parents mentioned that parenting a child with a disability has given them a new appreciation for other family members, especially their nondisabled children. A parent of a child with Down syndrome stated, "I look at my other kids differently. I never finished high school and I put a lot of my expectations on my [nondisabled] daughter. C____ taught me my children do not have to follow my goals for their lives. So, it's helped me to be a more open mom to my other kids, and to be supportive rather than to direct them." As well, other parents mentioned that their experiences have changed the ways they relate to people in general. One parent commented, "It's taught me that there are no meaningless persons. There are no throw-away people. Our society throws some people away. But everyone has something to offer." Others mentioned that they have learned to see life from the perspective of other people, especially people with disabilities. This has led several parents into roles as advocates.

Through advocacy several parents reported the exhilaration of knowing that they have "made a difference" in someone else's life. A mother of a child with Down syndrome spoke of how her life has been personally enhanced through advocacy. "I advocate for a young man who has spent a good deal of time in an institution. He calls me on the phone sometimes and giggles on the other end. The other day I heard him say his first words to me, over the phone. He said, 'I missed you.' That was something that revitalized me--hearing someone say for the first time, 'I missed you.'"

Probably the most common relational transformation expressed by these parents was that of expanding their friendship networks. A parent of a child with multiple disabilities stated, "I know a lot of wonderful people because of L____.

She's brought many people--wonderful people--into our lives." Parents expressed value in discovering that life is not built on independence, but on interdependence. "C____ taught me about interdependence, that who I am is really mediated through another person. I remember the day I recognized what interdependence meant. I had rebelled at the idea that C____ had to be dependent. But then I realized he's really interdependent, like we all are."

Relational transformation, whether through improved relationships with family members, new friendship networks, or advocacy relationships have in some way benefitted the majority of parents interviewed. Parents reported that, as will be described in greater detail in the next section, relationships have replaced material possessions or personal achievement as a highly valued component of life.

Theme 9: Perspectival transformations. Twelve parents interviewed (80%) related ways in which parenting a child with a disability has changed their perspective on life. Specifically, parents mentioned learning to value each day and to celebrate life, acquiring a more authentic conceptualization of success, and restructuring the priorities in their lives. A parent of a child with an unknown prognosis commented, "I guess it's caused me to look at what's real, what's important, and to live one day at a time, because I don't know how things are going to be from one day to the next. I think I appreciate life probably more than I ever used to. Every day I have with L____ is a new day and it's an important day, and I have to make the most of that day." Another parent similarly remarked, "I've learned to savour the moments. It's not 'quality of life,' but 'life as quality' that's important to me now."

Other parents have discovered that even life's small accomplishments are important milestones. A mother of a child with autism noted, "You learn not to take anything for granted. When my daughter learned to read, that was really exciting. But when L____ used one word, it was like a mountain. Celebration."

Parents also related a different perspective of how success is evaluated. One parent spoke of how her perception of success shifted from a goal-oriented perspective to an attributional emphasis. "We've come to realize that it's the effort that you put into something that helps you achieve success. Everybody has different levels of achievement. You take a little child and ask her to take one giant step and her step is going to be a lot smaller than someone who's taller and got longer legs. But she's done the best giant step she can do. So when we get N____'s report card, we look at the effort." Several parents addressed the difficulty of accommodating their children's ability with society's definition of success initially. However, as they began to adjust their expectations for their children, they found their own perception of success radically altered. As one mother said, "There are a lot more important things in life than money in the bank."

Some parents related that they began to differentiate between things that mattered in life, like people and values, and "petty things." Other parents related that they have learned to embrace life's sorrows as well as its joys through their encounters with children with disabilities and their parents. One mother commented, "I've learned more about life. I've met more sick children and more people that have really gone through difficult situations. I've gone through the death of one child with a friend. . . . I think it's brought a depth to my life that many people never experience. I guess it's caused me to look at what's real, what's important . . . like people and friends, and savouring the moments of life." Another mother commented that parenting a child with a disability "compresses life's lessons," enabling parents to develop an appreciation for the important things of life earlier than other people do. Another mother suggested that perhaps parents of children with disabilities have the opportunity to develop wisdom or discernment earlier than parents whose circumstances do not require them to confront some of the more difficult aspects of life until much later.

Many parents reported that how they view life changed following the diagnosis of disability in their children. Positive transformations focused on valuing each day, celebrating life, revising their views of success, and learning what is truly valuable in life. A number of parents related that they might not have discovered these important concepts had their families not contained children with disabilities.

In summary, each of the parents interviewed reported some positive transformations associated with parenting their children with special needs. Transformations included acquiring new roles and traits, developing and enhancing relationships with other people, and formulating more authentic ways of perceiving life. However, the question remained as to whether these experiences were unique to the fifteen parents interviewed or whether and how they could be extended to describe a greater number of parents. The Life Management Survey was constructed to answer this question. The results of this survey are presented and discussed in the following section.

Life Management Survey

Eighty copies of the Life Management Survey were returned by the deadline date and used in data analysis. Sixty-five (81.3%) responses represented two-parent families and 12 (15%) responses were from single-parent families. Sixty-three of the respondents (78.8%) resided in urban settings and 15 (18.8%) resided in rural localities. Sixty-four (80%) of the surveys were completed by mothers, 11 (13.8%) by fathers, one (1.3%) by a residential caregiver, and three (3.8%) by foster parents. Table 4 depicts occupations of mothers and fathers contained in the families that were surveyed, and Table 5 depicts highest education completed for mothers and fathers contained in the families that were surveyed.

Fifty-one (64%) of the children with disabilities were male, and 29 (36%) were female. Fourteen (18%) of the children were between 0 - 6 years of age, 33 (41%) were between 7 - 18 years of age, and 31 (39%) were 19 years or older. Child disabilities ranged as follows: visually impaired (9), hearing impaired (7), autism (17), Down syndrome (26), mild-moderate developmental delay (15), severe developmental delay (18), attention deficit hyperactivity disorder (5), learning disability (10), and other disability (9). [Note: due to the fact that

Table 4. Occupations of Surveyed Parents/Guardians

Occupation	n father	%	n mother	%	Total	%
Unemployed	1	1.3	0		1	1
Semi-skilled	7	8.8	2	2.5	9	6
Skilled	24	30.0	20	27.4	44	28
Professional	20	25.0	15	18.8	35	22
Homemaker	3	3.8	29	36.3	32	20
Retired	7	8.8	5	6.3	12	8
Student	0	0	2	2.5	2	1
Missing	18	22.5	7	8.8	25	16

some parents checked more than one disability condition, the total number of disabilities exceeds the total number of children included in the study.] Disability conditions listed in the "Other" category included Williams syndrome, Fetal Alcohol Effect, heart defect, Cerebral Palsy, Prader-Willi syndrome, Langer Gideon syndrome, spina bifida, and behaviour disorder.

Table 5. Highest Education Level of Surveyed Parents/Guardians

Level of Education	n father	%	n mother	%	Total	%
Less then 12 years	10	12.5	6	7.5	16	10
12 years	10	12.5	15	18.8	25	16
1-2 yrs. college	21	26.3	30	37.5	51	32
1-3 yrs. university	0	0	3	3.8	3	2
4 yrs. university	11	13.8	12	15.0	23	14
> 4 yrs. univ.	24	30	12	15.0	36	23
Missing	4	5	2	2.5	6	4

Finally, sixty parents (75%) indicated that they were involved in at least one parent support group. Thirteen (16.3%) indicated that they were not involved in a support group.

Analysis of Life Management Survey

The LMS was analyzed using SPSS 4.1 by tabulating for each item the frequency distribution, percentage, mean, and standard deviation scores. Survey Items #1 - #59 were cross-tabulated with demographic variables to examine life management from a variety of perspectives. Comments were collated according to survey item and analyzed qualitatively.

A "comment" was defined as any written response on the line(s) following each of the LMS statements. Comments ranged from one word to several sentences or, in a few instances, paragraphs. A total of 1,258 comments was made on the 80 surveys, resulting in a mean of 20.29 comments per survey item.

Section 1 on the LMS (Strategies) contained a total of 789 comments, with a mean of 24.66 comments per item and a range of 14 (Item #29) to 45 (Item #5) comments. Section 2 of the LMS (Parent Characteristics) contained a total of 193 comments, with a mean of 14.85 comments per item and a range or 10 (Item #13) to 31 (Other) comments. Section 3 (Transformations) contained a total of 276 comments, with a mean of 16.24 comments per survey item, and a range of 6 (Item #54) to 34 (other) comments. Therefore, the majority of comments were made to the statements comprising Section 1 (Strategies), followed by Section 3 (Transitions) and Section 2 (Parent Characteristics).

The survey statement receiving the fewest comments was Item #54 ("I have learned to see life from a different perspective") and the statement receiving the highest number of comments (45) was Item #5 ("to accept that my child's and family's success is entirely under the control of other people or external circumstances"). The comments associated with this statement confirm the effectiveness of the statement to reduce the possibility of "responder bias," that is, the likelihood that parents would agree or strongly agree with any or all the survey items without careful consideration of wording. The other statement included in the survey to check for responder bias was Item #19, ("to accept that I will always have to make decisions for my child") which generated the third highest number of comments (32). The majority of the comments contradicted this statement, though several of the comments indicated that a small number of parents felt that statement was, in fact, true for their situation.

While most comments made supported the conclusions from the qualitative analysis of parent interview, there were some comments which refuted, challenged or extended that data. Both kinds of comments will be examined along with the results of the survey according to the nine themes.

Theme 1: Reframing (Items #1 - #12). Table 6 summarizes the responses to Items #1 - #12 of the LMS covering the theme and sub-themes related to the strategy of reframing.

Strategies rated as most essential related to the sub-themes of acceptance of

Table 6. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme One: Reframing

Strategy	*n*	1 %	2 %	3 %	4 %	5 %	Mean	SD
1. Accept child	79	5.1	0	7.5	25.0	61.3	4.39	1.0
2. Value child's contribution	79	1.3	1.3	10	36.3	50.6	4.34	.8
3. Way child affects others	78	5.1	7.7	25.6	37.2	24.4	3.68	1.1
4. Consider child's goals	78	2.6	3.8	14.1	39.7	39.7	4.10	.9
5. Success externally controlled	59	57.6	18.6	13.6	10.2	0	1.76	1.0
6. Willing to accept help	76	2.6	6.6	26.3	36.8	27.6	3.80	1.0
7. Belief in a reason	77	13	3.9	23.4	28.6	31.2	3.61	1.3
8. Belief in positive outcome	77	2.6	3.9	23.4	46.8	23.4	3.84	.9
9. Trust own instincts	79	1.3	1.3	6.3	40.5	50.6	4.38	.8
10. Advocate self-confidently	79	0	1.3	1.6	43.0	49.4	4.41	.7
11. Adapt plans flexibly	76	2.6	6.6	26.3	30.3	34.2	3.87	1.1
12. Live life in the present	74	12.2	21.6	25.7	23	17.6	3.12	1.3

the child as he/she is (Items #1, #2, and #4) and enhanced feelings of competence and self-confidence (Items #9 and #10). Interestingly, while 64.5% of the respondents indicated that a very important or essential strategy is to adapt plans flexibly, only 40.6% associated that with living life in the present. Item #5, an inverted statement, was included to check for responder bias, since participants in the interview study indicated that an important strategy is to remain in control of child and family outcomes. While Item #5 had the fewest responses (59), the majority of parents (57.6%) considered this strategy not important. An analysis of the comments made to survey Items #1 - #13 further extends the results of theme 1.

While parents generally agreed that acceptance was important for building child- and self-esteem and promoting "family bonding," several parents remarked that it has been a difficult and, at times, lengthy process, especially when unacceptable child behaviours (e.g., swearing or undressing in public) were involved. Separating "child" from "behaviour" was at times a challenge for parents. Parents' comments clearly reflected that they love and value their children and believe that their children have had a positive impact on the lives of others, such as siblings, neighbours, and extended family members. While many parents also stated that it is very important to value their children's goals and dreams, 10 of the 27 comments (37%) attested to the difficulty of discovering what their child's goals are, due to the cognitive or communication limitations of the child.

Parents were adamant in their comments regarding the importance of maintaining control of child and family outcomes, though several remarked that it is difficult to sustain control when the "system" has its own agenda. And, while most parents acknowledged that a willingness to accept help is important, several remarked that finding suitable and supportive help is "extremely difficult." Parents were also divided in their belief that there is a reason why their child is in their lives. In response to that statement, 16 comments (73%) supported belief in a reason or purpose, while 6 comments (27%) denied a belief in purpose. All nineteen comments for Item #8 reflected that parenting a child with special needs has resulted in positive outcomes, though 1 parent remarked, "but I would never wish it on anyone."

Parents also felt strongly that they were best informed to make decisions about their children's needs, though 1 parent commented, "it's very easy to be intimidated by others, even when you have a good educational background." While parents agreed that developing self-confidence in advocating for their child(ren) was essential (e.g., "If I don't no one else will"), nine of the 22 comments regarding advocacy (41%) related that learning to advocate is a difficult process that takes a long time to master. Though 22 comments were made about the importance of being flexible, five comments stressed that living with indeterminacy can, in the words of one respondent, "cause considerable upheaval in life." And, while parents agreed that living in the present is an important strategy, nineteen parents (63%) stressed the necessity of establishing goals and objectives for the future.

In general, the results of the LMS Items #1 - #12 supported the findings of theme 1 and its sub-themes. Parents seemed to use the comment sections to temper their ratings, indicating that while these strategies are important, they are not necessarily easy to learn or employ.

Theme 2: Balancing Roles and Responsibilities (Items #13 - #18). Table 7 summarizes the responses to Items #13 - #18 of the LMS covering the theme and sub-themes related to the strategy of balancing roles and responsibilities. Once again, the results of the LMS generally supported the findings of the qualitative analysis. For those who are married, nurturing marriage rated the highest score in this section, with 79.4% of the respondents ranking it as either very important or essential. Second in ranking was the strategy of balancing time between all the children in the family, followed by guarding the role of mother/father and limiting

Table 7. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Two: Balancing Roles and Responsibilities.

Strategy	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
13. Safeguard physical and emotional health	76	1.3	2.6	38.2	25	32.9	3.86	.9
14. Nurture marriage	68	1.5	1.5	17.6	35.3	44.1	4.19	1.0
15. Setting limits on external expectations	76	0	3.9	22.4	47.4	26.3	3.96	.8
16. Balance time with all children	71	1.4	2.8	19.7	45.1	31	4.01	.9
17. Flexible occupation	74	4.1	9.5	27	33.8	25.7	3.68	1.1
18. Confident in public	79	2.5	3.8	24.1	40.5	29.1	3.90	.9

external expectations. Again, a look at the comments made to these survey items brings clarification.

Eight of the 24 (33%) comments made regarding Item #13 (safeguarding physical and emotional health) stressed the difficulties associated with implementing this strategy. Three factors that were specifically mentioned were lack of time, lack of energy, and lack of adequate respite care. Nevertheless, several parents associated emotional and physical health to their ability to care for their children. A number of parents also indicated that these same three factors were related to difficulties with nurturing their marriages. Not having time was mentioned by a number of respondents, though one commented, "we haven't always made the time." Four respondents indicated that their marriages did not survive and another stated that a separation had occurred. One also commented that marriage counselling had been helpful. Several spoke of the importance of building a strong marriage partnership to counter the many stresses of parenting a child with a disability.

While comments generally indicated that it was important to balance the roles of parent, teacher and advocate of their child(ren) with disabilities, several respondents remarked that the "system" has made it difficult to maintain such a balance due to the plethora of expectations placed on parents' shoulders. However, the majority of comments made by parents strongly supported the need to create balance, since they could easily be overwhelmed by the needs of their disabled child(ren). Fourteen respondents emphasized that giving equal time and attention to their nondisabled children was "almost an impossibility." For many parents this was an ongoing frustration. Others seemed to accept the unequal distribution of time and attention as a fact that needed to be accepted to maintain family health. Though this item (#16) received a high ranking on the survey, comments made by parents, again, served to qualify these responses.

The item receiving the lowest ranking in theme two related to flexibility in occupation/employment. This might have been due to the fact that approximately 40% of the respondents indicated that they were homemakers. However, some also remarked that parenting their child had affected their employment opportunities negatively. The respondents that seemed most satisfied and evidenced the highest employment flexibility were those who held part-time or job-sharing positions. Respondents indicated that employment flexibility was particularly important during times of child illness or to accommodate staff meetings, medical appointments, and interviews associated with their children.

Finally, several respondents remarked that feeling comfortable with their child in public places has become more difficult as their child has grown older, though a few commented that if they are unable to feel comfortable and confident, they should not expect others to do so. Comments reflected that knowing when to remain silent and when to speak out is, indeed, a balancing act, which involves both respecting the rights and privacy of their child(ren) while allowing a parent or caregiver to educate and inform others of issues surrounding disability.

Theme 3: Utilizing Resources (Items #20 - #25, #28). The responses to the survey items pertaining to utilizing resources are summarized in Table 8. These survey items received the lowest response ratings of the nine themes, particularly items regarding relying on support from the community, the church, and friends whose children do not have disabilities. Acquiring skills necessary for working with professionals received the highest rating for theme 3.

Yet networking with professionals received a number of negative comments, mostly due to the fact that some caregivers' perceptions of professionals is fairly negative. One respondent commented, "Almost without exception, I have found 'professionals' to be over-bearing, overly assertive, almost arrogant, lacking in sensitivity and warmth." Another remarked that "achieving a true team approach has been impossible." One respondent attributed this difficulty to lack of training to develop those skills which would be useful for networking. Finally, another remarked that "what one needs more than skill is stamina--to prevent burn out."

Table 8. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Three: Utilizing Resources

Strategy	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
20. Collaborating with professionals	78	0	1.3	18.8	41.3	37.2	4.15	.8
21. Parents of children with disabilities	77	2.6	14.3	27.3	32.5	23.4	3.60	1.1
22. Extended family members	73	5.5	24.7	28.8	26	15.1	3.21	1.1
23. Friends with nondisabled children	75	12	25.3	33.3	24	5.3	2.85	1.1
24. Community support	76	11.8	13.2	48.7	19.7	6.6	2.96	1.0
25. Church support	73	27.4	17.8	32.9	17.8	4.1	2.53	1.2
28. Gather information	74	1.4	9.5	27	28.4	33.8	3.84	1.0

Respondents were divided over the usefulness of connecting with other parents of children with similar disabilities. While the majority of respondents indicated that association with other parents was very important (e.g. "nothing has been more valuable"), a number remarked that there either were no parents or support groups available or that they have found them largely unhelpful.

Respondents' comments were divided as well over the usefulness of relying on extended family members for support. While for some, the support from family has been "essential," the majority of comments made indicated that distance from extended family members and other factors, such as time, energy, or age of extended family members, has inhibited extensive involvement. Similar comments were made with respect to reliance on support from friends whose children do not have disabilities, the community, and the church. While some respondents indicated that these were important avenues of support, the majority emphasized difficulties associated with these support options, such as prejudices, lack of awareness, understanding or acceptance, and lack of time or energy on the part of either or both groups. Finally, while gathering information was also important, several respondents remarked that due to the uniqueness of their children and/or their family situations, most information they have received has been of limited benefit.

Other useful strategies. The open-form response section following Part I of the LMS generated 33 comments concerning additional strategies parents have found helpful. They included such strategies as recognizing that things take time, securing necessary counselling or therapy, accepting failure at times (knowing when to give up), journalling, praying, crying, learning to live without answers, considering the worst possible scenario, ignoring or avoiding negative people, developing skills in time-management, and planning for positive outcomes. While some respondents mentioned that many of these strategies have been difficult for them to learn and use constructively, a few pointed out that these strategies are no different than those used to parent "normal" children.

Theme 4: Personal Character Traits (Items #32 - #41). A summary of the responses to the survey items pertaining to the importance of various personal character traits is found in Table 9. Respondents generally rated the parent characteristics high across the board. One parent characteristic, patience, was rated as "essential" by over 50% of the respondents. All other parent traits, except creativity, were rated as either very important or essential by the majority of respondents.

Table 9. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Four: Parent Characteristics.

Character Trait	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
32. Creativity	79	1.3	8.9	43	30.4	16.5	3.52	.9
33. Determination	78	0	2.6	15.4	44.9	37.2	4.17	.78
34. Flexibility	78	1.3	3.8	24.4	42.3	28.2	3.92	.89
35. Self-esteem	78	1.3	3.8	24.4	43.6	26.9	3.91	.89
36. Hopefulness	77	1.3	5.2	22.1	31.2	40.3	4.04	.98
37. Patience	77	0	5.2	13.0	29.9	51.9	4.29	.89
38. Positive outlook	76	0	0	17.1	38.2	44.7	4.28	.74
39. Resourcefulness	78	0	2.6	25.6	46.2	25.6	3.95	.75
40. Sense of humour	79	0	5.1	22.8	39.2	32.9	4.00	.89
41. Willingness to grow and learn	78	0	1.3	11.5	46.2	41.0	4.27	.71

Participants' comments, again, served to qualify these ratings. Several respondents agreed that determination has been essential to their success (e.g., "determination is the difference between reaching a goal and falling short"). Parents indicated that the key to effective determination is a strong belief in the value of what one is trying to accomplish. Parents also ranked flexibility as very important, both with respect to personal and family well-being and child outcome patterns (e.g., "without flexibility the special person would many times be on the sidelines").

Responses indicated that self-esteem, though important, can be fragile and variable in nature, especially involving difficult encounters with professionals. However, as one parent pointed out, "you need the confidence self-esteem brings [in order] to speak out." A number of respondents indicated that hopefulness is useful only when it is directed toward possibilities, rather than impossibilities (e.g., "there is no hope of a cure, but we always hope for a good life"). While some parents remarked that hope was "the only thing that brought [them] through a difficult time," they also stressed that false hope can only lead to frustration.

Respondents rated patience and resourcefulness as essential, both in dealing with specific child issues, such as difficult behaviours, and with problems surrounding the procuring of needed services for the child and family, like networking with social service personnel. Sense of humour was important to many parents because it "is the best medicine," "is contagious," creates a "happy environment," and "makes any situation lighter." However, parents cautioned that laughter can become "twisted" if it replaces the healthy expression of true emotion. Finally, willingness to grow and learn was important both to the well-being of the respondent and for the advancement of the child.

Other parent traits. Respondents listed a large number of other parental traits in the open-form response section following Part II of the LMS. These included stamina/energy, good communication skills/articulate/poised, high tolerance to slow moving bureaucracy or to prejudice, willingness to risk, ability to bounce back when hurt, self-reliant, realistic/reasonable, observant, and ability to stay focused. While parents/guardians generally ranked all parent characteristics high, they indicated that they did not always exhibit these traits consistently or proficiently.

Table 10. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Five: Decision-making and Problem-solving Ability

Personal Attribute	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
19. Accept primary decision-making	70	7.1	14.3	27.1	32.9	18.6	3.41	1.2
26. Creative problem solving	75	0	6.3	26.7	41.3	25.3	3.85	.88
27. Child part of decisions	74	2.7	0	33.8	33.8	29.7	3.88	.94
42. Solve problems effectively	75	0	4.0	28.0	46.7	21.3	3.85	.80

Theme 5: Decision-making and problem-solving ability. (Items #19, #26, #27, & #42). A summary of the responses to the survey items pertaining to decision-making and problem-solving ability is found in Table 10. Over 50% of the respondents ranked the four personal characteristics describing decision-making skills as either "very important" or "essential," though these ratings fell slightly below those for personal character traits.

Parent comments tended to qualify their rankings. While some parents responded negatively to always having to make decisions for their children, others remarked that it was important to accept that this was a true, though at times overwhelming, statement. Fears about the child's future were cited by several parents as contributing to personal and family anxiety. Other parents commented that they were training their children or others to become informed decision-makers in the event that they are no longer able to contribute to the decision-making process. Several remarked that they were "empowering" their children to make their own decisions and to acquire skills in self-advocacy. One parent reworded Item #19 to read: "to accept that I will always have to make decisions with my child." On the other hand, a number of parents reported that their children were incapable of making their own decisions due to age factors or cognitive limitations. Nonetheless, these parents attempt to ascertain and include their children's wishes or preferences when making decisions on their behalf.

One difficulty with decision-making cited by several respondents was that parent or family decisions may not always be implemented as planned, leading to feelings of frustration or implementation of unacceptable alternatives. Others remarked that while creative problem-solving is important, it often requires a considerable expenditure of time and energy related to scheduling and organizing meetings and appointments with a sizeable number of professionals. Yet, in spite of this, utilization of a team approach was the preference of a good number of respondents. Finally, one respondent indicated that cultivating problem-solving skills kept the family focused in a positive direction. "It's not where we are, it's where we are going that counts!"

Theme 6: Philosophy of Life (Items #29 - #31, & #43). A summary of the responses to the survey items pertaining to the importance of philosophy of life as a parent/guardian attribute is found in Table 11. Belief in a personal choice over life outcomes received the highest ranking, with over 80% rating it as either "very important" or "essential." This was followed by possessing strong personal convictions. Belief that adversity brings beneficial outcomes ranked third, while the

Table 11. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Six: Philosophy of Life

Personal Attribute	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
29. Belief in choice	76	0	3.9	15.8	46.1	34.2	4.11	.81
30. Benefits from adversity	76	1.3	10.5	36.8	38.2	13.2	3.51	.90
31. Things happen	75	10.7	14.7	36.0	28.0	10.7	3.13	1.1
43. Strong personal convictions	77	1.3	1.3	23.4	42.9	31.2	4.01	.85

more stoical belief that "sometimes things just happen, so looking for reasons is futile," received only a moderate ranking.

Respondents' comments indicated that, for many, belief in personal choice is associated with maintaining a sense of control over child and family outcomes. When people feel they have no choice about how they will live life, they are more likely to feel that they have no control over it, though one parent advised, "sometimes you have to accept 'what life makes of you.'" The belief that adversity brings out inner strengths was important for many respondents, though several mentioned there is a "down side" to this belief--"adversity drains after 21 years!" Others, however, cited benefits attained from times and experiences of adversity, and one respondent wrote that it has been important, even, to discover "how adversity can be embraced."

Respondents were divided over the constructiveness of the belief that things happen and searching for reasons behind them is futile. Six of the 26 comments to Item #31 asserted that there is a reason why things happen. Eleven of the comments confirmed the statement that things do, in fact, just happen. Interestingly, respondents on both side of the belief issue pointed out that regardless of their inner convictions, their primary goal was to go forward, or, as one parent commented, "move on." Another parent wrote that it is best to accept what life brings, unless discovering a reason behind it "is going to help improve [the child's life]." Another remarked that it is important to separate "reason" from "blame;" that is, while searching for a reason may be helpful, searching for where to lay blame is usually counterproductive.

Finally, parents associated strong personal convictions with the ability to remain persistent or determined in the face of difficulty (e.g., "without strong personal convictions you would give up"). Another remarked that if parents of children with disabilities did not hold strong inner convictions "institutions would still be here." Strong personal convictions keep parents "on track" as they strive to reach personal, child, and family goals.

Theme 7: Personal Transformations (Items #44 - #51). A summary of the responses to the survey items pertaining to personal transformations is found in Table 12. Over 50% of the respondents rated each of the eight personal transformation statements as either "agree" or "strongly agree." The statement receiving the highest ranking was "I have learned how to speak out," followed by "I am more compassionate," "I have learned I can achieve," and "I am stronger as a person." Though over 25% of the respondents rated the statements "I can laugh

Table 12. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Seven: Personal Transformations

Transformation	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
44. Speak out	79	2.5	0	6.3	38.0	53.2	4.39	.82
45. I can achieve	79	1.3	0	6.3	57.0	35.4	4.25	.69
46. Compassionate	75	0	0	9.3	50.7	40.0	4.31	.64
47. Laugh more	73	0	12.3	27.4	45.2	15.1	3.63	.89
48. Stronger	77	0	2.6	10.4	54.5	32.5	4.17	.71
49. More confident	76	0	5.3	26.3	44.7	23.7	3.87	.84
50. Better care of health	72	1.4	12.5	27.8	44.4	13.9	3.57	.93
51. Stronger spiritual convictions	77	6.5	16.9	23.4	23.4	29.9	3.53	1.3

more," "I am more confident," and "I take better care of myself" as "uncertain," again over 50% of the participants stated that they agree or strongly agree with these statements. The variability on the last statement, "I have stronger spiritual convictions," was greatest.

Respondents commented that their ability to speak out, which for some was a long and difficult learning process, stems largely from their desire to protect and support their children. Because their children with disabilities have faced greater discrimination and difficulties associated with accessing equal services, these parents have been forced to become more relentless in their pursuit of their goals for these children than they have had to be for their "normal" children. Therefore, though, at times, they have had to speak out on behalf of their nondisabled children, having a child with a disability has required them to speak out to a much greater degree.

Parents commented that speaking out for one's child is also related to perceptions of achievement and control, though several parents mentioned that feelings of empowerment versus powerlessness can change from day to day, depending on what (or whom) one is dealing with. Several respondents also mentioned that although they are less bothered by "trivial things," they are uncertain if that is actually associated with being able to laugh more. Perhaps it is more associated with a changed perspective regarding what is truly important in life. Several remarked that the experience of parenting a child with a disability has brought on periods of depression, though, in spite of these "down" times, they have experienced beneficial outcomes. Also, comments implied that cultivating a sense of humour is different from being able to laugh more. A sense of humour was perceived more as an outlook on life, while laughing more was associated with a type of grinning, overall "happiness" about life, with which they were unable to identify. Therefore, while parenting a child with a disability does not necessarily increase the "happy times," it does often put trivial incidents into perspective.

While some parents related that confidence has come from having to speak out and advocate on behalf of their children, they, again, were reluctant to associate confidence with being less "afraid" of life or of pain. Some shared fears concerning their child's future, yet others associated part of their perception of strength to the fact that they have been forced to look pain and suffering in the eye and have survived. While participants' comments confirmed that safeguarding their personal health is important, 50% of the parents/caregivers stated that they are less successful at this than they would like to be. Again, time, energy, and the demands of caring for a child with a disability are obstacles to achieving their personal health and well-being goals. However, several asserted that they are working to carve out time for their personal health needs. One participant commented, "Finding time for myself has been my greatest challenge. The joyous part is. . . I'm working on it now!"

Though respondents also mentioned that one outcome of parenting a child with a disability is that they now have stronger personal convictions, some were hesitant to associate this with faith in God. Faith in life, self, or one's private belief system were also cited as components of personal convictions.

Finally, it must be noted that many parents commented that these parent characteristics or traits were attributes that they already possessed to some extent prior to the diagnosis of disability in their children. Therefore, they were reluctant to consider them transformational outcomes of parenting these particular children, though some commented that the degree to which these outcomes have emerged may be a reflection of their parenting experiences.

Theme 8: Relational Transformations (Items #52 - #55). A summary of the responses to the survey items pertaining to relational transformations is found in Table 13. Respondents gave three of the four statements very high ratings. In fact, approximately 90% of the respondents either agreed or strongly agreed with the two statements "this experience has brought wonderful people into my life" and "I have learned to see life from a different perspective." The majority of respondents also agreed or strongly agreed with the statement, "I have made a difference in the lives

Table 13. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Eight: Relational Transformations

Transformation	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
52. Stronger marriage	69	7.2	18.8	21.7	33.3	18.8	3.38	1.2
53. Met other people	79	0	2.5	7.6	35.4	54.4	4.42	.74
54. See life from point of others	80	0	2.5	5.0	47.5	45.0	4.35	.70
55. Made a difference for others	78	2.6	0	14.1	47.4	35.9	4.14	.85

of other people." However less than 50% agreed that their marriages had emerged stronger. In fact, one-quarter of the respondents indicated that they either disagreed or strongly disagreed with this statement.

Nine of the respondents commented that their marriages have either been terminated or have deteriorated since their child's disability has been diagnosed. Nine others indicated that their marriages have emerged stronger. Several attributed this to the fact that their marriages were strong to begin with and they had already established effective and supportive patterns of relating. Thus, they were unable to differentiate if the strong marriage mediated effective life management, or if their marriages have actually been strengthened as a result of their experiences parenting a child with a disability. Others intimated that the presence of a child with a disability introduces other variables into family life, such as reduced or depleted finances, which in turn place greater strain on a marriage. One parent/caregiver commented that marriage outcome "has more to do with [spouse] than with child."

Commitment to remaining married has kept several couples together, though one respondent observed, "we remained married, but we are the 'odd' couple. The discord has taken its toll, . . . and while this can prove beneficial to the outcome, it does produce extreme stress [in] our relationship."

While a large number of comments supported the fact that participants have been changed through meeting wonderful people as a result of parenting children with disabilities (e.g., "My best friends I have met because of my child" and "I can't imagine what life would be like if I had not met them and they had not contributed to bringing out quality in my life"), one parent commented that "the opposite end of the spectrum is also true." Seven comments referred to meeting individuals who were "filled with hatred" and discrimination towards persons with disabilities. Others reported difficulties with professionals and the accompanying frustrations associated with these encounters. Still another respondent remarked, "Wonderful people have [also] gone out of my life as a result of my commitment to 'this experience.'" Many respondents cited other parents of children with disabilities and personnel from agencies serving persons with disabilities as the leading members of the "wonderful people" category. Several intimated that they might not have had relationships at this depth if they had not had a child with a disability.

In summary, it seems that while parents were generally in agreement with this statement, they also wanted to register the fact that there are two camps of people that they relate to as a result of parenting a child with a disability: the supportive people and the people who stand in their way. It may be true that having a child with a disability intensifies certain relational outcomes.

Though a few respondents commented that they were more able to see life from another perspective, several mentioned that their experiences have taught them that no one can ever, truly understand another person's situation, because each situation is unique. What they have been given, however, is a heightened appreciation of the value of life in general, a recognition of the dignity of each human being, and an ability to be "comfortable around people that are different." As well, as they have advocated for their own children, several commented that they have received satisfaction from knowing they have opened doors for those following them. Finally, while many reported positive relational transformations, several reported that other family members have also experienced similar beneficial outcomes.

Theme 9: Perspectival Transformations (Items #56 - #59). A summary of the responses to the survey items pertaining to perspectival transformations is found in Table 14. Over 80% of the respondents either agreed or strongly agreed with the statements regarding a more authentic view of success and knowledge of what is important and valuable in life. Over 70% agreed or strongly agreed with the statement "I make the most of each day," whereas only 63% agreed or strongly agreed with the statement, "I celebrate life more now."

While respondents' comments indicated that many try to make the most of each day, they also continue to keep the future clearly in mind (e.g., "I try to do

Table 14. Percentage, Frequency Distribution, Mean, and Standard Deviation of LMS, Theme Nine: Perspectival Transformations

Transformation	n	1 %	2 %	3 %	4 %	5 %	Mean	SD
56. Make most of each day	75	1.3	8.0	17.3	53.3	20.0	3.83	.89
57. Celebrate life	71	2.8	11.3	22.5	45.1	18.3	3.65	1.0
58. More authentic view of success	76	1.3	3.9	14.5	47.4	32.9	4.07	.87
59. Learned what is important in life	74	1.4	4.1	9.5	47.3	37.8	4.16	.86

both--enjoy the journey, but do something today to make tomorrow even brighter"). However, several respondents qualified their comments by affirming that their ability to make the most of each day is, at best, variable. One respondent remarked, "I sometimes wait for tomorrow, hoping it will be better than today." Similar comments were made to the statement "I celebrate life more now." While some affirmed that "life is a gift," others conceded that they "just survive day to day." Several also mentioned that their views of success have been modified; however, only two defined what "success" meant (e.g., "to feel happy and secure" and "quality of life").

The majority of comments supported changed perceptions of what is really important and valuable in life. Respondents mentioned such things as to serve others, to accept others without discrimination, to love, to be loved, to value and cherish life, to be valued as a person, and to cherish and savour family relationships (e.g., "it's not what we have, but who we have that makes it all worthwhile"). However, several respondents qualified these comments by indicating that it is these things as priorities (e.g., "some days 'yes,' some days I lose track of it") and put them into practice.

Other changes: Thirty-four respondents wrote comments, some of which were quite lengthy, in the open-form section entitled "other changes you have experienced." Many of these comments did not relate directly to transformations, but rather conveyed a final general statement regarding parenting a child with a disability. Since many of those statements were covered in other parts of the survey, only those comments pertinent to transformations were considered in this analysis.

Parents contributed a number of other ways in which they have been changed through their experiences parenting a child with a disability. These included a change in how they parent their other (nondisabled) children, the ability to discover and express emotions, a better understanding of the interdependence of life, a heightened awareness of social justice and equality issues, opportunities to speak, write and travel, and development of new talents or skills, such as leadership capacities, hobbies, volunteer work, or vocational interest areas.

A number of comments stressed the importance of balancing these positive transformations with the reality that negative changes have also occurred in their lives. Negative transformations mentioned included such things as health problems, increased stress, career limitations, growing cynicism, less trust in the establishment (e.g., government, agencies, medical personnel, and/or educators), loss of friendships or former relationships, and reduced participation in valued social or recreational activities. Therefore, parents seemed to indicate that, as with all things in life, there were negatives and positives, pluses and minuses, associated with parenting a child with a disability. While some parents assert that the strategies they use and the parent characteristics they view as important cannot be differentiated from those of parents who raise "normal" children, some of the transformations are associated specifically with parenting children with disabilities. While the experience is in many ways similar, in many other ways it is significantly different.

Cross-tabulations

Additional data analysis was performed by cross-tabulating responses from the 59 survey items with the demographic variables of parent status (two-parent/single parent), place of residence (urban/rural), gender of child, age of child (0-6, 7-18, 19 and older), membership in support groups, and survey respondent (mother, father, or other). Pearson product-moment correlations were computed to examine the relationships between these variables. The following is a summary of the significant correlations resulting from the analysis of the survey data.

One-parent, two-parent families. Sixty-five of the respondents (84.4%) indicated that they were from two-parent families, while 12 (15%) represented single-parent homes. It might be noted that several respondents from two-parent homes reported that their present spouses were step-parents of their child(ren) with disabilities. However, the relationship of spouse to the child was not taken into account in these correlations.

1. A weak, negative correlation existed between one- or two-parent families and the importance of being first and foremost the child's mother or father (Item #15) ($r = -.251$, $p < 0.05$). Single-parent respondents were more likely to rate this "important," while two-parent respondents were more likely to rate it "very important" or "essential."

2. There was also a weak, negative correlation between single/dual parent status and the strategy of gathering information about the child's condition (Item #28) ($r = -.262$, $p < 0.05$). Single parent respondents were more likely to rate this item as "important," while dual-parent respondents tended to rate it "very important" or "essential."

3. A weak, negative correlation was found between single-dual parent respondents and ratings of the parent characteristic of self-esteem (Item #35) ($r = -.262$, $p < 0.05$). Single parents were more likely to rate this item "important," while married respondents were more likely to rate it "very important."

4. Finally, a weak, negative correlation was found between marriage emerging stronger (Item #52) and single/dual parent responses ($r = -.278$, $p < 0.05$).

In summary, the cross-tabulations indicated that single parent respondents were less likely to consider being first and foremost the child's mother/father and gathering information about the child's condition as necessary strategies. Single parent respondents were less likely to rate self-esteem a necessary characteristic to success in managing life. Single parents/caregivers were also less likely to indicate that their marriages have emerged stronger as the result of parenting a child with a disability.

Urban/Rural Residence. Sixty-three (78.8%) of the respondents indicated that they resided in urban areas, while 15 (18.8%) reported rural residences.

1. Place of residence has a weak correlation with the parent characteristic "flexibility" (Item #34) ($r = .273$, $p < 0.05$). Rural parents were slightly more likely to consider flexibility a very important or essential characteristic.

2. There were weak correlations between place of residence and the transformational outcomes of being able to laugh more, less depressed (Item #47) ($r = .243$, $p < 0.05$), made a difference in the lives of others (Item #55) ($r = .238$, $p < 0.05$), making the most of each day (Item #56) ($r = .328$, $p < 0.05$), and learned what is really important and valuable in life (Item #59) ($r = .270$, $p < 0.05$). Rural respondents were more likely to rate these transformations higher than urban respondents.

3. A moderate correlation was found between place of residence and the transformational outcome of celebrating life more (Item #57) ($r = .422$, $p < 0.05$). Again, rural participants rated this item slightly higher than their urban counterparts.

Gender of child. Fifty one (63%) of the children were male and 29 (35%) were females. Several respondents did not indicate child gender.

The only significant relationship in the category of child gender was a weak correlation between gender and Item #12, to live life in the present (limit thoughts of the future) ($r = .308$, $p < 0.05$). Parents/guardians of females were more likely to rate this item higher than parents/guardians of males.

Age of Child. Child ages were separated into three categories (0-6, 7-18, and 19 and older) for analysis. Fifteen children (18.8%) were 6 years of age or under, 32 (40%) were between the ages of 7 and 18, and 31 (38.8%) were 19 or older.

1. There was a weak correlation between age of child and willingness to accept help (to acknowledge that I/we can't do it alone) (Item #6) ($r = .280$, $p < 0.05$). Parents of older children were more likely to rate this item higher, with the highest rating coming from parent of children 19 and older, followed by those whose children are between 7 and 18.

2. A weak, negative correlation was found between child age and belief in a reason for the child's presence in the parent's life (Item #7) ($r = -.276$, $p < 0.05$). The majority of parents of children six or younger scored this item "essential," while parents of children nineteen years and older tended to score it less high ("important").

3. A weak, negative correlation was found between child age and nurturing marriage (Item #14) ($r = -.249$, $p < 0.05$). The majority of parents of children age six and under rated this "essential," while parents of older children rated it less high.

Membership in Support Group. Sixty of the respondents (75%) indicated that they were involved in at least one support group, while 13 (16.3%) replied that they were not. Only one significant correlation was found for this variable.

There was a weak correlation between belonging to a support group and the strategy of connecting with other parents of children with similar disabilities (Item #21) ($r = .285$, $p < 0.05$). Respondents who belonged to support groups rated this item higher.

Gender of Respondent. Sixty-four (80%) of the surveys were completed by mothers, while 11 (13.8%) of the surveys were submitted by fathers. The remainder were completed by foster parents or residential caregivers.

1. A weak, negative correlation was found between survey respondent and flexibility in occupation (Item #17) ($r = -.236$, $p < 0.05$). Fathers were more likely to rate this strategy less important than mothers.

2. A weak, negative correlation also was found between survey respondent and the transformational outcome of learning to speak out on behalf of the child (Item #44) ($r = -.357$, $p < 0.05$), with fathers rating this item lower than mothers.

3. Finally, a weak correlation was found between survey respondent and the transformational outcome of stronger marriage (Item #52) ($r = .246$, $p < 0.05$). Fathers generally rated this item higher than mothers.

These weak correlations can only indicate possible data trends. Utilizing a larger data pool may generate more substantiative results. A discussion of the results of the study and implications for future research is contained in Chapter 5.

CHAPTER 5

Discussion

Summary of Findings

The purpose of this study was to examine ways in which parents/caregivers of children with a variety of disability characteristics and at a variety of age levels manage life effectively. More specifically, the study examined three aspects of life management: (1) strategies parents/caregivers used to manage life, (2) personal characteristics or attributes that parents/caregivers felt were important for effective life management, and (3) positive transformational outcomes associated with parenting children with disabilities. The objective was to explore universal properties of effective life management across child disability and age ranges.

The study was conducted by first reviewing the literature on family systems theory, coping and adaptation in general, coping in families containing children with disabilities, and transformational outcomes. Then a series of open-ended, semi-structured interviews were conducted with 15 parents representing 14 families containing one or more children with disabilities. A qualitative analysis of the interviews resulted in the formation of nine themes, three pertaining to life management strategies, three describing parent characteristics, and three summarizing transformational outcomes. These themes were confirmed by the parents during follow-up interview sessions. A 59 item survey instrument, the Life Management Survey (LMS), was constructed from the nine themes and their sub-themes. Sixty-two spaces were provided on the LMS for open-form comments. Finally, data from the LMS were analyzed using frequency distributions, cross-tabulations, and correlation tests. A content analysis of comments was also conducted.

The following is a summary of the results of the study.

1. The majority of parents interviewed stressed that an essential component of life management is the ability to reframe one's initial response of devastation regarding the diagnosis of disability in one's child to a more constructive attitude toward parenting a child with a disability. For the majority of parents this involved such things as accepting their child as he/she is, cultivating a determination to succeed, believing that there is purpose or meaning in their life's circumstances, acquiring the personal competence and self-confidence needed to parent a child with a disability, and living successfully with indeterminacy. These findings were supported by the analysis of survey data.

2. The majority of parents also affirmed that to manage life effectively they must continually strive to maintain a sense of balance between the various roles and responsibilities they carry. These include such factors as safeguarding their physical and emotional health, nurturing their marriages, balancing the roles of parent/teacher/advocate for their child(ren) with disabilities, parenting other children in their families, securing flexible employment, and educating society. These findings were also corroborated by the Life Management Survey.

3. The majority of parents interviewed cited utilization of a variety of

resources and social supports as essential to effective life management. These include locating information about their children's disabilities, collaborating with professionals, connecting with other parents of children with disabilities or parent support groups, and utilizing other sources of support like extended family members, churches, community members and organizations, and house-keeping services. The results of the LMS indicated that while these sources of support were helpful to many, there was some variability in the usefulness of resources such as professionals, churches, extended family members, and community members and organizations.

4. Parents interviewed concurred that certain parent characteristics are fundamental to effectively managing life with a child who has a disability. These characteristics include patience, flexibility, sense of humour, hopefulness, positive outlook, determination, resourcefulness, self-esteem, and the ability to grow and learn. The LMS confirmed these parent characteristics as well as introduced other characteristics such as good communication skills, ability to bounce back when hurt, ability to stay focused, stamina/energy, and tolerance. However, the degree to which these additional parent characteristics are more widely held was impossible to ascertain. As well, while some respondents indicated that these characteristics are no different from the attributes needed to parent any child, others remarked that the degree or extent to which these parent attributes are needed and employed in the parenting process is significantly greater when a family contains a child with a disability.

5. Parents interviewed supported the necessity of possessing good problem-solving and decision-making skills in order to manage life effectively. Though these were not rated as high as other items on the LMS, the results revealed that the majority of parents rated them as either "very important" or "essential."

6. Parents interviewed also attributed some of their parenting success to their personal philosophies of life or strong inner convictions, whether these involved beliefs such as the power of adversity to bring positive results, or a more stoic perception of their personal and family circumstances. Especially important to these parents is the conviction that one can, to an extent, control life outcomes. The results of the LMS strongly supported this conviction, though relatively less support was given to the more stoical interpretation of life events.

7. Parents interviewed cited a number of positive personal transformations associated with parenting a child with a disability. These transformations fell into two categories: (1) acquired roles, such as advocacy and leadership positions, and (2) acquired or extended traits, such as compassion for others, greater endurance, and an enhanced sense of personal strength. These transformations were confirmed by the LMS, though parents/caregivers were less likely to indicate such transformations as being less depressed, taking better care of self, and possessing stronger spiritual convictions than other transformations.

8. Parents interviewed described a number of relational transformations including changed relationships with family members (especially other children and spouses), acquisition of new friendships, and meaningful relationships formed

through advocacy involvements. The results of the LMS strongly supported these relational transformations, but with some variability on stronger marriage outcome.

9. Interview participants delineated a number of perspectival transformations, such as valuing each day, celebrating life, possessing a more authentic view of success, and establishing different and more beneficial life priorities. The LMS respondents strongly supported these transformational outcomes.

10. The large majority of comments made on the LMS open-form comment section were qualifying ("yes, but . . .") comments. Many respondents used these sections as opportunities to indicate that while they believed the survey statements were important ingredients of effective life management, it neither negated the difficulty of implementing some of the strategies or parent characteristics nor consistently reduced the pain or worry associated with parenting a child with a disability.

11. The small number of respondents in certain LMS demographic categories may have affected the strength of the resultant correlations, the large majority of which were weak. Therefore, significant correlations at this point might be viewed as possible trends that would need to be corroborated by a larger data sample.

Relation to Previous Research

The results of this study are congruent with much of the literature pertaining to stress and coping in families containing children with disabilities. Therefore, rather than cite literature that corroborates these research findings, this section will examine those areas where the findings of this study either extend or challenge existing research.

Reframing and Life Management. The results of this study indicate that the ability to reframe one's initial negative thoughts and attitudes about one's circumstances is an important component of life management in families containing children with disabilities. This concurs with research that indicates that one's ability to reinterpret, or reappraise, a stressful event and its impact on one's personal or family life is an integral element of coping and adaptation (Gordon & Song, 1994; Meichenbaum & Fitzpatrick, 1993; McCubbin & McCubbin, 1993; Wikler, 1986). Several researchers go so far as to suggest that in general how one appraises, or, in this case, reframes, a stressful event may actually be foundational to determining differences in individual outcome when similar stressors are present (Gordon & Song, 1994; Ireys et al., 1994; Lazarus, 1993; Wikler, 1986). Therefore, the reframing process may be more important for effective life management for parents of children with disabilities than some of the existing literature has detected.

This study suggests that this generalized observation regarding reframing does apply to disability situations. Participants in this study spoke ardently of their belief that they were free to choose how they would respond to the diagnosis of disability in their children and to their role as parents of children with disabilities. Several commented that they believed their life management outcomes were more effective because in the midst of many challenges they were able to focus on the more positive aspects of their circumstances. Thus, they avoided becoming entangled in the difficulties of parenting a child with a disability. Therefore, the ability to reframe initial feelings of devastation to a more hopeful or constructive assessment may be pivotal to whether parents of children with disabilities go on to manage life effectively or not. Furthermore, it might be hypothesized that the process of reframing directly influences ways in which parents utilize other strategies, such as collaborating with professionals or acquiring skills for advocacy.

If it is true that reframing is a key to explaining individual differences in managing life, perhaps more attention should be focused on the appraisal and reframing processes of parents of children newly diagnosed with disabilities. Pennebaker (1990) asserts that using some form of language to relive a stressful experience is associated with improved psychological outcome. Language provides a vehicle through which a person may be better able to reframe and manage his or her perceptions associated with the stress. Respondents in this study indicated the benefits of employing such language techniques as journalling or keeping a diary, talking with a sympathetic listener, or engaging in positive self-talk. Professionals might keep in mind the benefit of such techniques.

Determination to be successful. Parents/caregivers indicated throughout this study that they believed part of their success in life management was due to their intense desire to be successful. This raises the question as to whether motivation or drive to succeed are just as important to life management as are acquisition of effective strategies or the procurement of resources, both mentioned in the literature as positive influences on coping. Lazarus (1993) has recently acknowledged, "my own work and that of others has mistakenly divorced coping from the broad goals and situational intentions that powers and directs it along with stress and distress. Not only does coping belong within the rubric of finding solutions, but it also falls within the realm of motivation; this realization brings new insights into how coping strategies are influenced" (p. 36). Although the relationship of motivation to learning ability has been noted (Ames, 1992; Borkowski, Carr, Rellinger, & Pressley, 1990), much of the literature on stress and coping in families containing children with disabilities overlooks the motivational aspect of coping.

If it is true that motivation influences, or perhaps even drives, the coping process (and this study would indicate that, at the very least, it is a component of it), supporting and encouraging parents of children newly diagnosed with disabilities to persevere doggedly in the midst of their obstacles might be a primary responsibility of professionals. It may be plausible that deeply embedded motivational schemas exist which influence strategy utilization and outcome. Professionals, then, might conceive of themselves more as coaches and cheerleaders of parents, striving to motivate them to trust their own abilities and instincts, as well as assisting them in various other capacities.

Self-confidence, competence, and self-esteem. This study indicated that life management is enhanced by the acquisition of competence in skills necessary to parent a child with a disability, supported by the self-confidence needed to advocate on behalf of that child. Research on learning indicates that one's attitude toward one's ability, or competence, to influence outcomes is directly related to personal success (Borkowski, 1990; Covington, 1987; Harter, 1982).

Other literature suggests that self-esteem, or having a high regard for one's value and worth, is also associated with positive parent outcomes (Meichenbaum & Fitzpatrick, 1993). Brooks (1994) emphasized the relationship between self-esteem and positive outcome in resilient children, and Turnbull and Turnbull (cited in Turnbull et al., 1993) used the term "cognitive coping" to describe a way of viewing one's circumstances that results in, among other things, enhanced self-esteem. Since self-esteem was not particularly mentioned by the interview participants (in fact, several intimated that they had rather low self-esteem) the question became one of discerning whether references to self-esteem in the literature merely depicted perceptions of self-confidence and personal competence.

For this reason, self-esteem was included in the LMS and the results indicated that, indeed, self-esteem was considered an important parent attribute. Comments implied that self-esteem, self-confidence, and personal competence are strongly interrelated aspects of life management. It might be hypothesized that increased parenting competence enhances both self-confidence and self-esteem. Allowing for this hypothesized relationship might assist professionals who work with parents of children with disabilities. Happily, Cunningham et al. (1993) found that it is actually possible to facilitate improvements in parent perceptions of competence through group problem-solving sessions.

Control and Indeterminacy. A substantial amount of research contends that one's perception of personal control over one's circumstances, or locus of control, is related to positive outcomes in a variety of stress conditions (Antonovsky, 1993; Friedrich, 1985; Meichenbaum & Fitzpatrick, 1993; Miller et al., 1992; Rimmerman, 1991; Stovya & Carlson, 1993; Taylor, 1983; Turnbull & Turnbull, 1993). Assuming and maintaining personal control is also considered by some a characteristic of resilient individuals (Barnard, 1994; Brooks, 1994). The participants in this study agreed that having control over things like decision-making processes was vitally important. Yet, paradoxically, they also claimed that an important component of effective life management has been the ability to live successfully with indeterminacy, or a lack of control, both with respect to daily plans and future considerations. While acknowledged in the parent-authored literature, this counterpoint emphasis is rarely mentioned in the professional literature on coping pertaining to parents of children with disabilities.

While the establishment of control is for obvious reasons highly desired, one's affective response to factors one is ultimately unable to control may be equally or even more critical to successful life management. This study suggests that there may be a sense in which control must be differentially applied to various aspects of parenting children with disabilities. While respondents strongly supported the necessity of maintaining control over child and family outcomes, they also indicated that flexibility and the ability to adapt plans at a moment's notice is necessary for effective life management.

Resilience and Effective Life Management. The participants in this study seemed to value and share many of the same characteristics that literature attributes to resilient individuals. Such characteristics as the ability to form close relationships, the ability to give a positive interpretation to life events, an internal locus of control, facility in problem-solving, and a healthy marital dyad, are found in both resilient individuals (Beardslee, 1989; Brooks, 1994; Gordon & Song, 1994) and in the participants in this study. Therefore, the question arises as to whether the parents/caregivers who participated in this study are examples of resilient individuals who possessed the attributes associated with resiliency prior to the diagnosis of disability in their children. In other words, it may be argued that the study of effective life management is simply a study of resilient individuals who happen to be parents of children with disabilities.

If this is true, then the challenge becomes one of ascertaining the extent to which resiliency can be acquired, or whether resiliency, like temperament, is to a large extent an inherent trait. At the very least, this study has shown that parents who manage life effectively utilize identifiable strategies in order to be resilient. Self-perceptions indicated that many of these strategies and parent attributes developed subsequent to the diagnosis of disability in the child.

Effective Life Management and Hope. Hope has been described as both a state and a trait (Farran, Herth, & Popovich, 1995). That is, it both reflects one's immediate feelings about a particular circumstance, as well as depicts an orientation toward life in general. Farran et al. (1995) portray hope as an "energizing force"

(p. 5) which frees a person to develop creative responses to the problems of life. Hope, they also claim, can be sustained in the face of the most negative prognoses and can result in beneficial personal transformations. Hope has been linked to positive coping outcomes (Jevne, 1991), even though it remains unclear whether hope stimulates positive coping, is itself a coping strategy, or is a result of coping successfully (Farran et al., 1995).

Personal traits identified in the literature as characteristic of hopeful people, such as accepting pain as a part of life, engaging in positive thinking, and deriving beneficial outcomes from negative life experiences, are similar to those personal characteristics identified in this study as important to life management by parents of children with disabilities. However, the professional literature pertaining to parents of children with disabilities rarely mentions it. Participants in this study rated hope as a very important attribute for parents of children with disabilities. It may even undergird the philosophy of life of those who maintain a strong belief that good can come of adversity. This study suggests that hope is an important component of life management, especially when hope is invested in an attainable goal. In fact, some participants stated that hope was the only thing that kept them going through some of their "darkest" moments. Therefore, they value people who offer them hope. On the basis of this attestation, it may be important for professionals to endeavour to engender hope in parents, even when the immediate outlook appears bleak.

Transformational Outcomes. Research contends that stressful events that come as a sudden shock, affect many life domains, and challenge one's basic assumptions about life often result in transformations (Aldwin, 1994; Janoff-Bulman, 1992; Palus, 1993). Some researchers even profess that these permanent changes in self-perception, behaviour, or outlook on life may be necessary to resolve a crisis event and maintain mental health (Janoff-Bulman, 1992). Though references to positive parent transformations are found in the writings of parents of children with disabilities (Badry et al., 1993; Meyer, 1986), the professional literature rarely mentions them as a possible outcome of parenting a child with a disability.

The results of this study indicate that transformational outcomes do, indeed, take place in the lives of parents/guardians of children with disabilities. In fact, the statements regarding transformational outcomes received some of the highest ratings on the LMS. Clearly, parents and guardians are experiencing positive changes in their lives, changes many of them attest would not have occurred apart from parenting a child with a disability.

Parents resent the supposition that living with a child who is disabled must be a distressing and difficult experience. While they would be the first to admit that there are times when life is exceedingly difficult and want others to recognize how difficult parenting a child with a disability can be, they would also ardently attest to ways in which they have been transformed personally, relationally, and perspectivally through their parenting experiences. Aldwin (1994) theorizes that transformations may be foundational to positive personal health outcomes during encounters with stress. If this is so, then the professional literature in the field of disabilities should begin to address these acknowledged life changes in parents.

Implications of the Study

Implications will be discussed under two headings: (1) implications for professionals who work in the field of disabilities, and (2) implications for further research.

Implications for Professionals Who Work in the Field of Disabilities.

Many of the findings of this study are relevant for professionals who are involved in the field of disabilities. Several implications have already been mentioned in the previous sections and will not be repeated here. Rather, this section will briefly examine several additional important implications.

1. While many parents involved in the study indicated that strengthening their marriages was very important for effective life management, they were frank about both the difficulties involved with this and the breakdowns that can occur in marriage relationships. Some parents felt that professionals who were highly involved in the care of their children had little time to inquire about how they were managing as individuals or as a couple. Clearly, couples recognize the importance of a strong marriage to life management success. Professionals, in turn, must begin to deal more directly with parents as a dyad and assist them to both find and implement strategies to keep their marriages strong. Certainly adequate respite services and the financial assistance necessary to procure them are needed.

2. Many participants in this study expressed frustrations about the myriad of

expectations they felt professionals were placing upon them. In spite of days that are crowded with working and parenting other children, they have been instructed to set aside blocks of time for activities such as physiotherapy and speech training. While acknowledging the importance of these therapies, some parents spoke of feeling overwhelmed by the expectations, even to the point of personal burn-out. The challenge for the professional, then, is to reduce inordinate expectations of parents of children with disabilities and yet accomplish the necessary training goals. One possible method is to embed therapies into daily routines instead of requiring separate therapy sessions. As well, professionals might encourage parents to work toward setting manageable expectations by recognizing both the strengths and limitations of their own unique situations.

3. As a consequence of the expectations placed on parents to become teachers and advocates on behalf of their children with disabilities, many parents also shared their frustrations over being neither supported nor encouraged in what they felt was their most primary role, that of being the child's parent. Parents indicated that they needed support for and recognition of the importance of their parenting role from the professionals with whom they work.

4. This study uncovered a number of negative perceptions that parents and caregivers of children with disabilities have toward professionals. Unfortunately, many of these perceptions were not unfounded. While respondents recognized the frustration professionals might feel when there are no easy answers to difficult situations or when a negative prognosis is feared, they nevertheless resented

professionals who were arrogant, critical, insensitive, or entrenched in one-way thinking. Parents value professionals who collaborate with them as members of a team, rather than those whose goal is to "train" them from positions of authority. Some parents also indicated that assistance to acquire skills useful for collaboration would have been helpful in their children's early years. Clearly, professionals as a group need to be aware of the possible negative image of professionals that parents bring to parent-professional interactions. Perhaps some professionals should be challenged as well to examine their perceptions of parents.

5. Finally, parents simply need more professionals to draw alongside of them and say, "You're doing a good job." Lack of affirmation from professionals has intensified the alienation some parents of children with disabilities feel from professionals. Parents strongly affirm that because they know their child best, they are also most qualified to determine what he/she needs. Professionals might find that affirmation of parents and the knowledge and abilities they possess facilitates more constructive collaboration.

Implications for Further Research. The results of this study can be useful for stimulating further research in the field of disabilities in several ways. First, this study has implied that relationships might exist between effective life management, hope, and resiliency. Further research might explore these relationships, resulting in a more detailed portrayal of parents who manage life effectively.

Secondly, family systems theorists concur that one cannot understand how families operate without also understanding something about the environments in which they operate. While participants in this study represented a variety of backgrounds educationally, vocationally, and in places of residence, there may have been aspects of their family environments that may have been similar. This study examined several environmental aspects such as input from neighbourhoods and flexible, supportive employers. Further research might examine additional aspects of the environment that parents consider important as they manage life with children with disabilities.

Further research might also probe the tension between indeterminacy and control in the lives of parents whose children are disabled. Assisting parents to take control of the aspects of their lives that are controllable while relinquishing those things over which they have little or no control might lead to more effective personal and family management.

Finally, this study has explored and documented the perceptions of transformational outcomes in the lives of parents of children with disabilities. Further research might refine the understanding of these beneficial outcomes and ways in which that knowledge could benefit other parents and families.

Limitations of the Study

Research methods can undoubtedly affect the outcome of a study. Several limitations stemming from methodology used in this study are apparent at the outset. Some have already been mentioned in Chapter 3. This section will examine other limitations that must be considered when evaluating the results of this study.

1. There is always danger that use of a methodological design will control the conclusions that arise from a study. Certainly this study is no exception to that concern. Strategies, parents attributes, and transformational outcomes that were not mentioned by the interview participants were not included on the LMS. The provision of space for open-form written comments on the survey was intended to compensate for this limitation. Though the spaces were widely utilized by respondents, there is no guarantee that participants responded in a manner fully commensurate with their own experiences.

2. Experimenter effects are those cues given overtly or covertly by the researcher that influence the responses of the participants. Participants in a study who are aware that they have been judged to be managing life effectively may be influenced to describe their strategy usage and personal aptitudes more positively than they might under other circumstances. Thus, their own preconceptions of the qualities of good life management and their judgements of responses expected by the researcher may have biased their responses.

3. Instrumentation in this study involved the ability of the researcher to develop both an interview technique and a survey design that fostered candour and openness on the part of the respondents. The researcher utilized techniques such as bracketing and careful phrasing of questions and comments to minimize the threat of experimenter bias. Use of the interview guide approach in which parents were encouraged to tell their own story was also intended to deal with this limitation.

4. The small number of respondents in some survey categories limited the extent to which correlational analyses were applicable. A larger data base would have contributed to more convincing results.

5. The research was restricted to the province of Alberta which may limit generalization to parents/guardians who reside in other locales where, for example, supports available in Alberta may not be accessible.

6. The research was facilitated by personnel from a variety of agencies. This might account for the fact that close to 75% of the respondents indicated that they were involved in at least one support group. If this percentage does not reflect the true situation in the parent population, and it may well not, the conclusions of the study may not be a true reflection of parents who manage life effectively. Therefore, it may be helpful to repeat the study using a sample gathered through different sources.

7. Finally, agency personnel may have nominated participants who did not strongly match the definition of a person who is managing life effectively, even when this definition was clearly communicated to them. As well, certain participants chose not to complete and return the survey which may have skewed the conclusions of the study.

Due to these limitations, this study cannot pretend to give a comprehensive picture of life management in families containing children with disabilities. It is intended, however, to expand the present knowledge of life management by examining strategies utilized by parents with children who span a wide range of disability characteristics and ages. The inclusion of questions dealing with life management strategies, parent attributes, and transformational outcomes was intended to give breadth to the understanding of what it means to manage life effectively as a parent of a child with a disability.

Many parents of children with disabilities have expressed the frustration of having little information on how to begin the journey of parenting a child with a disability, as well as managing their own personal lives, their marriages, their work, and their immediate and extended families. The goal of this thesis was to provide such parents with a road map describing how others are successfully meeting the challenges of life and have been personally enriched along the way.

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APPENDIX A

PARENT INTERVIEW CONSENT FORM

I, ____, agree to participate in the parent-interview project of Dr. L. Wilgosh, on coping strategies for families which have a child with a disability. I understand that I can withdraw at any point if I do not wish to continue with the interview. I agree to having the interview audio-taped, with the understanding that the tapes will not be identified in any way, to guarantee confidentiality of my name and personal comments. After the interview the tapes will be transcribed, with deletion of any personal identifying information mentioned during the interview, and the tapes will be erased. Coping strategies mentioned by parents will not be associated with individual parent identities.

____
(Parent signature)

____
(Date)

APPENDIX B

Appendix B

Sample Qualitative Analysis

	I: What do you do when you see her suffer? When you know she's in pain and there's not a whole lot that can be done? How do you cope with that?
Theme 2: Physical Health (breakdown) Theme 3: Support (another parent) Theme 2: Child Characteristics Theme 2: Physical Health (breakdown)	R: I mean, I've had some trouble coping over the years, for sure. There was one time when I fell apart at the hospital. I just said, "I can't do this any more." Another parent who actually works at the hospital came and supported me. I was just exhausted. I hadn't slept for all of 2 weeks. Because, L____, she has neurological problems. Kids with neurological difficulties have trouble sleeping; and I kinda fell apart and actually ended up in the hospital for 10 days, and I just needed to sleep.
Theme 1: Personal Choice Theme 1: Determination to Make It Work	So, after that I decided that I wanted to be on the side of coping instead of not coping, and I wanted to have L____ with me--she was at the babysitters during the time. And that I just wanted to make this work.
Theme 2: Relationship with Child (guilt over role of parent) Theme 4: Parent Attribute (patience) Theme 4: Parent Attribute (positive outlook)	And I think my biggest guilt--when you were asking that question earlier--is sometimes feeling like I'm not being the best parent. Like, I have a tremendous amount of patience. I realize that. I finally turned some of this around and realized I have a tremendous amount of patience, but sometime's even that's not enough with a really challenging child. So I try to give myself credit instead of feeling--looking at the deficit areas. I try to look more positively.

Theme 7 & 9: Transformation	And there was a change. There's no question about it. Somewhere along the way there was a shift.
	I: Something gradual?
Theme 3: Parent Support Groups (Description)	R: Yeah. And a lot of it was listening to the--there was a parent support group in the preschool program. And because L___ came back to the program she was literally in the program for 4 years. I got the opportunity--and I was the only parent that stayed group after --I got the opportunity to hear the stories of other parents.
Theme 3: Support Parent Groups (positive and negative perceptions)	There's two parents that I still keep in contact with, that I really connected with. There was also the other side, where you meet the parents. There was one group, I think I was in a total of about 6 groups--and there was one group of parents who were the most negative, miserable people I have ever met.
Theme 1: Personal Choice Theme 1: Positive vs. Negative Reframing (Avoiding people who are negative) Theme 9: Transformations Positive Thinking	And I thought, "I don't even want to be like this, and I don't care to be around these people." Because, what they're becoming is martyrs and victims of their children's disabilities. And I found it really difficult to be a part of that group. I found it got me down. And because all they focused on was the difficulties. And that's part of my transformation, I think, in terms of looking at the positive side of things. Was to hear that.
	I: So, it was important to be there.
Theme 1: Personal Choice	R: To decide I don't want to become this. To see that contrast compared to the other groups who were really relatively quite good, was very interesting.

APPENDIX C

Life Management Survey

Please check the appropriate alternatives, or fill in the blanks.

Family Information

☐ Two-parent family or ☐ Single-parent family. If only one parent: ☐ Mother ☐ Father

Brothers and Sisters: Number:_______ Age(s):________________

Other family members in home (other than parents and siblings):

Number:_____ Relationship (e.g., aunts, grandparents):____________________

Residence: ☐ Urban (City) or ☐ Rural

Family Membership in Support Group(s): ☐ No ☐ Yes

Please list:____

____

Child Information

Child with disabilities: ☐ Son or ☐ Daughter

Age of child: _____

Disability: (check one category that best describes your child):

☐ Visual Impairment ☐ Hearing Impairment ☐ Autism ☐ Down Syndrome
☐ Mild to Moderate Developmental Delay ☐ Severe Developmental Delay
☐ ADHD ☐ Learning Disability

☐ Other Please describe:_________________________________

Parent/Guardian Information

Person filling out questionnaire: ☐ Mother ☐ Father ☐ Other

If other, please describe:_________________________________

Father/Guardian occupation:_______________________________

Mother/Guardian occupation:_______________________________

Years of Schooling (Indicate for Father and/or Mother):

less than 12 years	☐ Father	☐ Mother
12 years	☐ Father	☐ Mother
1 or 2 years of college or technical training	☐ Father	☐ Mother
4 years of university	☐ Father	☐ Mother
more than 4 years of university	☐ Father	☐ Mother

Questionnaire

Part I: Effective Strategies

Indicate how important each of the following **strategies** has been to your success in managing life as the parent of a child with special needs.

1. To accept my child as he/she is (i.e., to not be ashamed).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

2. To value what he/she brings to our family (i.e., sense of humour, sense of completeness).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

3. To consider how he/she has positively affected the lives of other people (i.e., made others feel like they belong).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

4. To discover what my child views as important (i.e., child's goals, dreams).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

5. To accept that my child's and family's success is entirely under the control of other people or external circumstances.

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

6. To acknowledge that I/we cannot do it alone (i.e., willingness to accept help).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

7. To believe there is a reason why my son/daughter is in my life.

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

8. To believe that parenting a child with special needs has positive outcomes (i.e., I have benefited from this experience).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

9. To believe that I know as well as anyone else what is right for my child (i.e., trust my instincts, value my opinions).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

10. To feel self-confident as an advocate for my child (i.e., not afraid to speak out, feel capable).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

11. To learn to adapt plans at a moment's notice (i.e., to be flexible, to take things in stride).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

12. To live life in the present (i.e., limiting thoughts of the future, dealing with the here and now).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

13. To safeguard my physical and emotional health (i.e., getting away, dealing with negative emotions).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

14. To nurture my marriage (i.e., time with spouse, open communication, sense of being a team).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

15. To be first and foremost my child's mother/father (i.e., setting limits on external expectations, balancing the roles of parent, teacher and child advocate).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

16. To find the appropriate balance of time and attention between all my children (i.e., dealing with unequal distribution of time, balancing fairness and responsibility).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

17. To be flexible in my occupation/employment (i.e., flexible hours, ability to make schedule changes at short notice).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

18. To learn to feel confident with my child in public (i.e., know when to speak out, when to stand up for child's rights, how and when to explain child's behaviour to others and when not to interfere).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

19. To accept that I will always have to make decisions for my child (i.e., be the primary decision-maker).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

20. To develop skill in working with professionals (i.e., overcoming frustrations with the system, encouraging a team approach).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

21. To connect with other parents of children with similar disabilities (i.e., active involvement in parent groups or organizations, seeking other parents out in time of crisis).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

22. To rely on support from extended family members (i.e., grandparents, parents, aunts, uncles, cousins).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

23. To rely on support from friends whose children do not have disabilities.

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

24. To rely on support from the community (i.e., neighbours, community organizations, community parent groups).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

25. To rely on support from the church (i.e., support from pastor/priest or members of the congregation).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

26. To engage in creative problem solving (i.e., explore possibilities, decide on a plan of action, carry out plans).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

27. To allow my child to be part of the decision making process (i.e., child assists in making choices).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

28. To gather information about my child's condition (i.e., reading, going to the library, collecting/categorizing material).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

29. To act on the belief that life is what you make it (i.e., you have a choice about how you will live life).

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

30. To believe that adversity brings out inner strengths.

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

31. To believe that sometimes things just happen, so that looking for reasons is futile.

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:____

Other strategies that work for you:

____

Part II: Parent Characteristics

Indicate how important each of the following **personal characteristics** has been to your success in managing life as the parent of a child with special needs.

32. Creativity

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

33. Determination

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

34. Flexibility

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

35. Self-esteem

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

36. Hopefulness

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

37. Patience

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

38. Positive Outlook

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:

39. Resourcefulness

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

40. Sense of Humour

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

41. Willingness to Grow and Learn

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

42. Ability to Solve Problems Effectively

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

43. Strong Personal Convictions

☐ Not Important ☐ Somewhat Important ☐ Important ☐ Very Important ☐ Essential

Comment:______________________________

Other parent characteristics important to you:

____

____

____

____

Part III: Parental Changes

The following statements express how some parents feel they have been **changed** through the experience of having a child with a disability. Indicate the degree to which you personally agree or disagree with each of these statements.

44. I have learned to speak out for my child (rather than remain passive).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:______________________________

45. I have learned I can achieve (rather than feel powerless).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

46. I am more compassionate toward others (less self-focused).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

47. I can laugh more (less bothered by trivial things or depressed).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

48. I am stronger as a person (rather than weaker).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

49. I am more confident (less afraid of life or of pain).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

50. I take better care of myself and believe my personal health is important.

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

51. I have stronger spiritual convictions (faith in God).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

52. My marriage has emerged stronger.

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

53. This experience has brought wonderful people into my life (people I never would have met otherwise).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

54. I have learned to see life from a different perspective (learned what it is like to live in someone else's shoes).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

55. I have made a difference in the lives of other people (I have learned to be an advocate).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

56. I make the most of each day (rather than living for the future).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

57. I celebrate life more now (rather than just merely surviving day to day).

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

58. I have a different and more authentic view of what it means to be successful in life.

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

59. I have learned what is really important and valuable in life.

☐ Strongly Disagree ☐ Disagree ☐ Uncertain ☐ Agree ☐ Strongly Agree

Comment:____

Other changes you have experienced:

____

____

____

____

Thank you for your help!

APPENDIX D

COVER LETTER TO SURVEY PARTICIPANTS

15 November 1995

Dear Parents & Guardians:

I am writing this letter to invite your participation in a study which is highlighting life management strategies common to parents of children with disabilities. So many parents have indicated that when initial diagnosis of disability in their child was made, they were given little information about how other parents and families managed life successfully. It is hoped that the results of this project will help to provide this essential information to parents of children newly diagnosed.

This study has already documented some interesting parent responses, especially in the area of how parents and family members have been changed in positive ways through their experiences of parenting a child with a disability.

At this stage your personal input is invaluable to me. I would especially like to know what has helped you to manage life successfully as a parent. I am therefore inviting you to take a few minutes to consider the attached survey and to return your completed responses to me in the envelope provided.

You may be assured that the data collection process has been specifically designed to protect the identity of all participants. Please do not put your name on any of the forms enclosed. If you would like to be included in this study, it is important that you complete and mail the Life Management Survey by December 22.

As a doctoral student in the Department of Educational Psychology at the University of Alberta, I have been encouraged with the enthusiastic participation of so many parents in this study thus far. Thank you for your consideration and your participation.

Sincerely,

Kate Scorgie, M.A.
University of Alberta

APPENDIX E

FOLLOW-UP LETTER

10 January 96

Dear Parents & Guardians:

This is a brief follow-up note to all of you who were recently invited to fill out a Life Management Survey. The purpose of this survey is to gather information on how parents of children with disabilities successfully manage their lives and, in a number of significant ways, have been positively changed through their experiences.

We have been gratified by the good level of response to the survey to date. If you are among those who have already returned a completed form, I want to take this opportunity to thank you for the time and energy you put into the task in the midst of the busy Christmas season. As anticipated, your input and perspectives are proving most valuable.

For those of you who have not yet had an opportunity to complete the survey, and still desire to do so, we are extending the deadline for mailing in the surveys to January 26. Please take a few minutes to register your responses. We do value each contribution.

If you would like another copy of the survey, please call the Alberta Association for Community Living, Edmonton office, at 451-3055 and another will be sent out to you promptly. Let me also say that we have appreciated the support and assistance of Bruce Uditsky and his staff in the Edmonton office with this project. Be assured once again that this study has been designed to protect the identity of all participants.

We extend our thanks to everyone for their interest, insights and participation.

Sincerely,

Kate Scorgie, M.A.
University of Alberta